The triangle of care for elderly patients

Exploring the relationships between elderly patients with multimorbidity and their care professional and social network

Kirti Devika Doekhie

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The Triangle of Care for Elderly Patients

Exploring the relationships between elderly patients with multimorbidity and their care professional and social network

De driehoek van zorgverlening voor oudere patiënten

Verkennen van de relatie tussen oudere patiënten met multimorbiditeit en hun zorgverleners en sociale netwerk

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CHAPTER 1

General introduction

General introduction

Mrs C, 84 years old

"My daughter is like a precious diamond. Ever since my husband died and my osteoporosis and asthma worsened, she helps me with many things around the house, such as cleaning and cooking. But more importantly, she helps me stay in control of my health situation and life. Because of my illnesses, I receive care from different care providers such as the pulmonologist in the hospital, the general practitioner, physiotherapist and home care nurses. She is the contact person to these persons and keeps track of my medical appointments. Without her, I would be lost."

Mr. F, 76 years old

"My health condition has recently deteriorated due to a cardiovascular condition and cancer. My eldest son has always helped me with things around the house and I highly appreciate his help. However, he now feels the strong urge to attend every medical appointment and take control over the appointment. The other day, my general practitioner asked me how I feel about starting a second round of chemotherapy. My son immediately said, "Of course my father will start the second round, he will do anything to save his life", since he is afraid to lose his father. But I know my general practitioner finds my son too dominant and wants me to make the decision on my own. I actually would rather have the general practitioner tell me what is best for me, since I really do not know what to do. But I am afraid to tell this to both of them."

POLICY CONTEXT

Mrs. C and Mr. F are two of the interviewed elderly in this thesis. Their stories are exemplary to the situations of many elderly patients living at home, facing challenges in dealing with their (chronic) conditions, together with their formal and informal caregivers.

In the past decades, the prevalence of elderly had rapidly increased. It is estimated that in 2030, one in four Dutch citizens will be 65 years or older, which means that the number of elderly will outnumber the number of young people (aged 0-20 years) (Central Bureau for Statistics, 2018). Especially the number of 'oldest elderly' (aged 80 years or older) will rapidly increase. In the recent Covid-19 pandemic, the mortality rate of elderly is higher than that of young or middle-aged patients (Liu, Chen, Lin, & Han, 2020). However, it is yet unclear whether the pandemic affects the future prevalence.

An ageing population is associated with a high prevalence of multimorbidity, defined as 'the co-existence of two or more chronic conditions' (Boyd & Fortin, 2010; Marengoni et al., 2011). A higher exposure to risk factors of chronic conditions (e.g., obesity, smoking

and excessive alcohol consumption) has contributed to this increase (Palladino, Tayu Lee, Ashworth, Triassi, & Millett, 2016). Depending on the study population and definition, the prevalence of multimorbidity of elderly across the globe varies between 55 percent and 98 percent of the total number of elderly (Fortin, Stewart, Poitras, Almirall, & Maddocks, 2012; Marengoni et al., 2011; Nunes, Flores, Mielke, Thume, & Facchini, 2016; Pefoyo et al., 2015). Next to their multimorbidity, many elderly suffer from problems such as mobility problems and incontinence, which could lead to social problems (Van Damme, Neiterman, Oremus, Lemmon, & Stolee, 2020).

Due to the expected increase of elderly people with multimorbidity, health policy-makers of many countries are challenged by balancing the provision of health and social care to these people and the efficient use of scarce resources. In response, many western European countries such as the Netherlands, United Kingdom and Sweden have reorganized the division of responsibilities over care and support provision between the state, municipalities, communities (e.g., informal caregivers, neighbours) and patients. The main responsibility over (social) care has been decentralized from the state to the municipalities and communities (Pavolini & Ranci, 2008; Tonkens, 2011; Verhoeven & Tonkens, 2013). At the same time, people are stimulated to live at home for as long as possible (ageing in place), to take more responsibility and to rely on their social network for care and support, leading to a more prominent role for informal caregivers (Price, Surr, Gough, & Ashley, 2020; Vos, van Boekel, Janssen, Leenders, & Luijkx, 2020).

Given these trends, care and support is organized in communities and closer to elderly patients' homes with a larger emphasis on integrating care delivery among different care professionals. Because of their multimorbidity, these elderly people rely on the support and care from various organisations and (primary) care professionals with different disciplinary backgrounds, such as a general practitioner, home care nurses and physiotherapists (Bähler, Huber, Brüngger, & Reich, 2015; Ngangue et al., 2020; Platzer et al., 2020; van Dongen et al., 2016). These multidisciplinary teams (also named interdisciplinary or interprofessional teams) and the inclusion of informal caregivers in the caregiving process, are essential in providing good quality care to elderly patients.

However, professionals with different backgrounds who need to work as a multidisciplinary team are not always acquainted with each other and could be unfamiliar with each other's roles. Teamwork between different professionals is faced with various challenges, such as distrust, unbalanced power and authority, poor communication, limited understanding of others' roles and unclear professional boundaries in care delivery (Baker, Egan-Lee, Martimianakis, & Reeves, 2011; Bradley, Ashcroft, & Noyce, 2012; Dey, de Vries, & Bosnic-Anticevich, 2011; Karam, Brault, Van Durme, & Macq, 2018; Khoshab, Nouhi, Tirgari, & Ahmadi, 2018; Reeves et al., 2015; Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017; van Leijen-Zeelenberg et al., 2015; Young et al., 2011). Baker (Baker et al., 2011) for example shows that physicians more often consider themselves as 'team leaders' and 'decision-makers', while other professionals prefer a holistic approach to care in which all professionals are equal 'team members'. Physicians feel that their authoritative position can be justified by the number of years of their training, but also because in a patient trajectory, they are considered liable in case of errors. These types of challenges could lead to negative attitudes among professionals of competition on tasks and responsibilities in care delivery or not wanting to work as a team at all. In turn, poor teamwork is shown to cause lower patient safety and inefficiency (Reeves et al., 2017).

CONCEPTUALISING TEAMS

An extensive amount of literature focuses on teamwork and team effectiveness in different health care settings (Buljac-Samardzic, Dekker-van Doorn, van Wijngaarden & van Wijk, 2010; Lemieux-Charles & McGuire, 2006; Michan & Rodger, 2000), though teams are often differently conceptualised. Within the stream of literature discussing the nature of teams in the past decades, a transition in perspectives on team characteristics is evident. Traditionally, teams were more seen as clearly bounded and fairly stable entities of a limited group of people, often a minimum of two individuals (Katzenbach & Smith, 2008; Michan & Rodger, 2000; Salas, Dickinson, Converse, & Tannenbaum, 1992). These entities often share a common goal, are task interdependent and are collectively accountable for team outcomes (Kozlowski & Bell, 2013; O'leary, Mortensen, & Woolley, 2011; Tannenbaum, Mathieu, Salas, & Cohen, 2012). Within these types of teams, people often perform coordinated tasks separately but in close interaction and exchange resources when necessary (Wageman, Gardner, & Mortensen, 2012).

In light of a changing health care context (e.g., changing demographics, higher multimorbidity rates) demands on teamwork and the structure of teams have changed. Many researchers propose a needed change to how teams should be examined, both theoretically and empirically, by taking on a more dynamic perspective on teams (Ale Ebrahim, Ahmed, & Taha, 2009; Mortensen & Haas, 2018; Tannenbaum et al., 2012; Wageman et al., 2012). Especially the boundedness of teams is central in this discussion (Wimmer, Backmann, & Hoegl, 2019). First, present-day teams are more and more expected to quickly adapt to changes in their dynamic context and the structure of these teams therefore needs to be fluid (Dibble & Gibson, 2018; Mortensen & Haas, 2018; Summers, Humphrey, & Ferris, 2012; Tannenbaum et al., 2012). Within literature on team fluidity, teams are often conceptualised as containing multiple layers similar to an onion (Tannenbaum et al., 2012). The inner circle consists of those individuals whose competence and activities are always necessary. These team members play an essential role in the team and remain part of the team throughout its lifetime. In the outer layers are individuals who are solely part of the team when their specific skills set and competences are needed for specific team tasks (Mortensen & Haas, 2018; Tannenbaum et al., 2012). In other words, these members have a more short-term team membership and are flown in for a specific task and flow out when their task has ended. Second, present-day teams often overlap as individuals hold membership in multiple teams simultaneously (Bertolotti, Mattarelli, Vignoli, & Macrì, 2015; Cummings & Haas, 2012; O'leary et al., 2011). This phenomenon is often referred to as 'multiple team membership' (Mortensen, Woolley, & O'Leary, 2007; O'leary et al., 2011) or 'multi-teaming' (Matthews, Whittaker, Moran, Helsley, & Judge, 2012). Third, present-day team members are often dispersed by being affiliated to different organizations, working in different geographic locations or different times zones (Gibson & Gibbs, 2006). Team dispersion is especially driven by a greater need for flexible and efficient resource utilization, as it creates opportunities for efficient use unrelatedly to an individual's location (Mortensen & Haas, 2018). Dispersed teams are often seen as 'virtual teams' as they have fewer chances to communicate face-to-face and therefore more rely on technological tools for communication and interaction such as videoconferencing (Ale Ebrahim et al., 2009; Gibson & Gibbs, 2006).

Also, present-day teams should be seen as multiteam systems (MTS), defined as "two or more teams that interface directly and interdependently in response to environmental contingencies toward the accomplishment of collective goals" (Mathieu, Marks, & Zaccaro, 2002). An MTS is a network of teams which perform different tasks and may have different team goals than the MTS goals (DiazGranados, Dow, Perry, & Palesis, 2014; Zaccaro, Dubrow, Torres, & Campbell, 2020). To illustrate, primary care teams could be seen as an MTS network consisting of members of different teams and organisations, such as home care nurses' teams, physiotherapists teams and occupational therapists teams. Ultimately, the goal of an MTS is to provide good quality care. However, in a patient journey, challenges on how to approach the care of a patient can occur between professionals. For example, home care nurses tend to assist or take over daily tasks, such as preparing meals and setting the table, while physiotherapists are more focused on stimulating patients to remain independent, for example preparing meals and setting the table themselves or with minimal support. Therefore, the effectiveness of multi team systems relies on teams and its members having a holistic perspective on caregiving and sharing objectives and tasks (Mathieu, Heffner, Goodwin, Salas, & Cannon-Bowers, 2000).

Teams in healthcare

In conceptualising teams in health care settings, the interdisciplinary or interprofessional character, (professionals with a variety of backgrounds and competences) is most emphasised (Xyrichis & Ream, 2008). Xyrichis and Ream (2008) conceptualise teamwork in health care as "*a dynamic process involving two or more health professionals with complementary backgrounds and skills, sharing common health goals and exercising concerted physical and mental effort in assessing, planning or evaluating patient care*". Bookey-Bassett and colleagues (2017) specifically focus on health care teams in the context of care for elderly patients with multimorbidity

living at home. Engaging elderly patients and their family members is considered a key attribute to multidisciplinary teamwork in this context, mainly to provide holistic care that addresses a patient's functional, psychological and social challenges (Bookey-Bassett et al., 2017; Engel, Prentice, & Hicks, 2019; LaDonna et al., 2016).

The emphasis on patient and family engagement in the team fits within the changing perspective on care delivery from professional-centred to patient-centred care. Patient-centred care can be defined as "*a collaborative, bidirectional relationship between health professionals and patients that intentionally involves the patient in decisions throughout treatment and care*" (Engel et al., 2019). In other words, when delivering patient-centred care is pursued and this care is delivered by a multidisciplinary team, a patient and his/her family members should be included in that team and be involved in the decision-making process (LaDonna et al., 2016).

The, desired, level of patient involvement varies between patients and is dependent on different patient and professional related factors, such as type and stage of illness, age, educational and cultural background, health literacy and the relationship between patient and professional (Brabers, Rademakers, Groenewegen, van Dijk, & de Jong, 2017; Davis, Jacklin, Sevdalis, & Vincent, 2007; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009; Thompson, 2007). Also, though informal caregivers are important in providing everyday functional and emotional support (Kennedy, Vassilev, James, & Rogers, 2015; Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016), their support can both strenghten and hinder patient involvement. For example, informal caregivers can help patients in asking questions and retrieving important information, but can also take on a dominant role in medical consultations and take over from the patient (Gallant, Spitze, & Prohaska, 2007; Wolff, Clayman, Rabins, Cook, & Roter, 2015; Wolff et al., 2017).

Nevertheless, many studies on interprofessional teamwork still address patients solely as recipients of care or not mention the patient at all; research that discusses a patient's role in terms of active patient involvement is limited (Engel et al., 2019; LaDonna et al., 2016). Patients and informal caregivers are rarely conceptualised as team members or asked who is part of their team (LaDonna et al., 2016). LaDonna and colleagues show that patients themselves play a role in their care team as active partners in decision-making rather than passive recipients of care. Moreover, patients do not only have professionals as team members, but also individuals within their social network such as family, friends and neighbours as these individuals provide care and support (LaDonna et al., 2016).

RESEARCH QUESTIONS AND METHODOLOGY

This aim of this thesis is to gain more insight into the teamwork and interactions between primary care professionals, informal caregivers and elderly patients and the effect of these interactions on patient involvement and self-management.

Part A addresses the first research question: What is a primary care team and what are the perspectives of team members on their own role and those of others in the team?

Firstly, part A focuses on the professionals' perspectives on the conceptualisation of primary care teams and their own role and those of other professionals. Because of elderly patients' multimorbidity, multiple primary care professionals with different backgrounds are often expected to collaborate in the care for a single patient. These collaborations are often labelled as primary care teams, but it is unclear if presumed team members actually consider themselves part of the same primary care team. Also, their perceptions of team membership could be misaligned (Mortensen, 2014). With a mixed-method approach, part A first focuses on primary care professionals' conceptualisations of primary care teams and their perceptions of which other disciplines they consider part of their team. After a survey study among 152 primary care professionals from 12 different disciplines, 32 semi-structured interviews with different primary care professionals from 5 disciplines were conducted, to gain a deeper understanding of the survey results. The interviews focused on the factors underlying perceptions of feeling part of a team and viewing others as team members (Chapter 3).

Secondly, part A zooms in on the triads of patients, informal caregivers and primary care professionals, specifically the role of patients in terms of involvement in the decision-making process. Elderly patients, and often also their informal caregivers, are more and more expected to take on an active role in the team by being involved in the decision-making process regarding their health. However, considering patients' different health situations and health literacy skills, it is questionable whether patients are able to take on this active role and if so, to what extent. We conducted 64 semi-structured interviews with elderly patients, informal caregivers and primary care professionals with different professional backgrounds to gain a better understanding of the (different) perceptions and expectations of the level of patient involvement in the decision-making process (Chapter 4).

Part B of this thesis addresses the second research question: *How do the relationships between elderly patients, informal caregivers and primary care professionals influence patient involvement and self-management of daily life?*

Part B focuses on two interaction processes within the triads of patients, informal caregivers and professionals: mutual trust and subjective norms. Also, Part B zooms in on how patients' perceived social network support (e.g., from friends and neighbours) influences their involvement in the decision-making process. Trust can be seen as a keystone of relationships between individuals (LoCurto & Berg, 2016; Wiechula et al., 2016). In healthcare, trust is often examined in terms of the level of trust of a patient in their care provider. However, in light of the growing emphasis on more self-management of their health situation and daily life, we also focused on the trust of the informal caregiver and home care nurse in patients' self-management competences. Subjective norms are social norms that refer to the expectations of persons considered important, such as informal caregivers and home care nurses (Brabers, van Dijk, Groenewegen, & de Jong, 2016). Subjective norms may lead patients to act in such a way they believe is expected from them by the other person. We investigated the (mis)alignments on the subjective norms within the triads in relation to the role of the patient in the decision-making process (Chapter 5).

To explore trust and subjective norms, we conducted a survey study among elderly patients, their informal caregivers and the most frequently involved home care nurse in the care for that patient. This led to data on the interactions in 39 unique triads of patients, informal caregivers and home care nurses. We specifically included home care nurses as chronically ill patients often receive home care for a long period of time. All patients received care from one large home care organization in Rotterdam (the Netherlands) and all nurses worked for this organization. Data was collected between July 2016 and December 2017 (Chapter 6).

Part C addresses the third and last research question of this thesis: *How can teamwork in primary care be improved and social network support be stimulated?* To answer this question, a systematic literature review and an intervention study were conducted. The systematic review was conducted to gain a broad overview of team interventions in different health care settings aimed at improving team performance. Therefore, no restrictions were laid on the type of intervention, health care setting, team type or research design. The systematic literature search included articles published between 2008 and 2018. The broad scope led to an oversight of researched team interventions in the primary care settings but also insight into what type of interventions in other health care settings could be beneficial in the primary care setting (Chapter 7).

Lastly, part C reflects on the implementation process of a digital web-based intervention named NetworkMAP (Network – Mobilizing Active Partnerships) from the perspectives of the users and researchers. The intervention was designed on the basis of a combination of insights from the previous chapters on team conceptualisation and interventions that improve team performance. In dealing with their (chronic) conditions, patients are not solely in contact with their primary care professionals. They also receive care and support from a network of for example informal caregivers, (extended) family and friends. NetworkMAP was designed provide elderly patients with more insight into their social support network via a generated personalised network map, showing the care professionals, informal caregivers, friends and family and other network members who provide care and support. The hypothesis behind the intervention was that by visualising their network, elderly patients would have more insight into the type and level of support they currently receive and identify possible gaps in their support system. This insight could encourage patients to strengthen their support network by making more frequently an appeal to current network members or including new members into their network, thus stimulating social network support. Twenty patients installed the NetworkMAP tool on their personal electronic device. Their actual usage of and experiences with the tool were measured multiple times during a five-month period (Chapter 8).

OUTLINE OF THIS THESIS

Chapter 2 in this thesis begins with a brief overview of the theoretical concepts of teams, team membership, patient involvement and self-management.

In addressing the first research question, chapter 3 in Part A of this thesis begins with a conceptualisation of primary care teams from the perspectives of different primary care professionals, also focusing on the underlying factors influencing their perception of team membership. Following the discussion that patients are also expected to be part of their primary care team, chapter 4 focuses on the role of elderly patients in primary care teams, in terms of their involvement in the decision-making process, from the perspectives of professionals, informal caregivers and patients themselves.

Part B of this thesis examines the relationships and interactions between patients and their (social) networks, also focusing on how these networks influence the patient's involvement and self-management. Chapter 5 elaborates on the role of mutual trust in triads of patients, informal caregivers and home care nurses and how trust influences self-management. Chapter 6 focuses on how the social context of elderly patients, specifically the subjective norms underlying the relationships of the triads and social support, and the influence of social context on patient involvement.

Part C of this thesis elaborates on interventions that could improve and stimulate teamwork and social support within networks. Chapter 7 is a systematic review of team interventions aimed at improving teamwork within the healthcare setting. Chapter 8 is a reflection on the implementation of an intervention aimed at visualising the social networks of elderly patients to enhance their insight into the social support potential of their network members.

Chapter 9 contains the summary and a critical reflection and discussion on the main findings and methodological issues of this thesis. Also, the recommendations for practice and future research are discussed.

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CHAPTER 2

Conceptualising the theoretical concepts: teams, team membership, patient involvement and self-management

This chapter provides a deeper understanding of the theoretical concepts in this study: teams and networks, team membership, patient involvement and self-management.

TEAMS AND RELATED CONCEPTS

Several researchers pay specific attention to the labelling of entities as "teams" and the concept of "real" teams (Allen & Hecht, 2004; Lyubovnikova, West, Dawson, & Carter, 2014; Naquin & Tynan, 2003; Sinclair, 1992; Wageman, Hackman, & Lehman, 2005; Wageman, Gardner, & Mortensen, 2012; West & Lyubovnikova, 2012; West & Lyubovnikova, 2013). Also, the term 'team' is often used interchangeable with terms such as (interprofessional or interdisciplinary) collaboration, group and network. However, different scholars have paid specific attention to the differences between these concepts (Berlin, 2010; Gilley & Kerno, 2010; Reeves, Xyrichis, & Zwarenstein, 2018; Saltman et al., 2007).

Described as 'the romance of teams', Allen and Hecht (2004) discuss the general assumption that working in teams is superior to working in groups. Consequently labelling groups as "teams" is appealing and often done. Different studies have however shown that teamwork is not always effective (Lemieux-Charles & McGuire, 2006; Naquin & Tynan, 2003). According to Naquin and Tynan (2003), the general supposition that working in teams is effective stems from the 'team halo effect', the phenomenon that team members themselves and outsiders tend to credit successes more often to the team as a whole than individual team members. Vice versa, low team performance and failures are often assigned to individual team members. The term "team" in this perspective could therefore be seen as a managerial trend word that is often assigned to different groups regardless of their functioning.

With regard to the terminology, collaborations and teams are often seen as surrogate concepts as they share similar aspects such as having a shared goal (Henneman, Lee, & Cohen, 1995; Xyrichis & Ream, 2008). In the concept analysis of Petri (2010), interprofessional or interdisciplinary collaboration in health care are interchangeable concepts and seen as "*an interpersonal process characterized by health care from multiple disciplines with shared objectives, decision-making, responsibility, and power working together to solve patient care problems*" (Petri, 2010). However, Xyrichis and Ream (2008) in their concept analysis of teams argue that the degree of interdependency and shared decision-making defines the difference between a collaboration and a team. To illustrate, during a daily collaboration in a general practitioner's office, a general practitioner might ask a practice nurse for input on a decision, but the ultimate decision is made by him/herself. Also, the final decision might be made regardless of the nurse's input. Thus, interdependent collaboration and shared decision-making is lacking, defining this relationship as a collaboration and not as teamwork, according the concept analysis of Xyrichis and Ream (2008). Groups are often considered to be more loose collaborations, in which individuals act separately and solely have to inform each other on their activities, instead of working together towards a common goal as teams do. Having a shared goal could be seen as a main defining feature of teams in comparison to groups (Saltman et al., 2007). In contrast to groups, teams are considered to be more focused on the relational aspects of their collaboration (e.g. trust building), function more autonomous and members are held mutually accountable for team goals (Gilley & Kerno, 2010; Saltman et al., 2007). Regarding networks, multiple researchers argue that in networks in contrast to teams, individuals are more loosely connected and focus more on coordination, but less on having a shared identity, role clarity, interdependency and a shared responsibility (Dow et al., 2017; Reeves et al., 2018). Network tasks compared to team tasks are seen as less complex and urgent (Reeves et al., 2018).

Team dimensions

In addressing the team concept, several authors have emphasised different team dimensions. Among others Richardson, Hackman, Wageman and West and Lyubovnikova discuss the distinction between "real teams" and so-called "pseudo-teams" (Hackman, 1987; Lyubovnikova et al., 2014; Richardson, West, & Dawson, 2008; Wageman et al., 2005; Wageman et al., 2012; West & Lyubovnikova, 2012; West & Lyubovnikova, 2013). However, the authors have different views on the the distinguishing dimensions of real team. Both Wageman and colleagues (2005) and Richardson and colleagues (2008) address the boundedness of teams in their definition of teams. However, the first only proposes three defining dimensions (i.e. clear boundaries, interdependency and a moderate degree of membership stability) (Wageman et al., 2005), while the latter propose six dimensions of real teams (i.e. team interdependency, team objectives, team reflexivity, team autonomy, team member role clarity and team boundedness (Richardson et al., 2008).

Richardson and colleagues (2008) define real teams as "a group of people working together in an organisation who are recognised as a team; who are committed to achieving clear team objectives upon which they agree; who have work closely and interdependently in order to achieve these objectives; whose members are clear about their roles within the team and have necessary autonomy to decide how to carry out team tasks; and who communicate regularly as a team in order to reflect upon the team's effectiveness and how it could be improved".

West and Lyubovnikova (2012) define pseudo-teams as "a group of people working together in an organisation who call themselves or are called by others a team; who have different accounts of team objectives; whose typical task require team members to work alone or in separate dyads towards disparate goals; whose team boundaries are highly permeable with individuals being uncertain over who is a team member and who is not; and/or who, when they meet, may exchange information but without consequent shared efforts towards innovation". In their commentary in 2012, West and Lyubovnikova (2012) discuss four dimensions of real teams: interdependency, shared objectives, reflexivity and boundedness. Interestingly, in their study in 2014, Lyubovnikova, West and colleagues (2014) do not discuss the boundedness and propose that real teams are solely defined by the interdependency, shared objectives and reflexivity. This implies that real teams are not restricted to members working in the same organisation. To conclude, though the authors have different perspectives on real time, consensus exists on team interdependency as a dimension of real teams.

Hollenbeck and colleagues propose differentiating team types based on three underlying dimensions rather than dichotomous variables: skill differentiation, authority differentiation and temporal stability (Hollenbeck, Beersma, & Schouten, 2012; Lee, Koopman, Hollenbeck, Wang, & Lanaj, 2015). Skill differentiation refers to the extent to which team members can be substituted based on their specialised knowledge or competences. Teams with low skill differentiation are more interchangeable because they do not fulfil a unique role, whereas teams with high skill differentiation consist of members with unique knowledge or competences. Authority differentiation refers to the extent to which decision-making responsibility is vested in individual team members, subgroups or the whole team. At one end of the continuum are teams in which a formally assigned leader makes all decisions; at the other end are teams in which team members themselves make all decisions, for example self-managing teams. Temporal stability refers to the extent to which team members have a working history together and expect to work together in the future. At one end of the continuum are fairly stable teams with members that have a history of working together and are likely to work together in the future. On the other end are teams with members who only work together on a short-term basis, for example ad-hoc on a project (Hollenbeck et al., 2012).

TEAM MEMBERSHIP

Following the traditional perspective on teams, team membership in terms of distinguishing members from non-members, has long been defined by the boundaries of teams (Mortensen & Haas, 2018; Wimmer, Backmann, & Hoegl, 2019). In the dynamic perspective on teams as fluid, overlapping or dispersed, team boundaries are more blurred creating challenges in distinguishing members from non-members. For example, team fluidity can cause difficulties in keeping a cohesive picture of the team, as the composition of the team changes over time. Also, multiple team membership (Mathieu et al., 2002) can cause confusion on which teams individuals belong to as it is difficult to keep track of their membership. Mortensen and Haas (2018) therefore propose changing how team membership is theoretically defined, from 'team membership' to 'team participation'. According to the authors, 'membership' is a binary concept. In other words, individuals can either be member or not be a member. The concept of 'team participation' is more continuous, acknowledging that individuals can participate in different teams to varying extents, in varying roles and in varying times.

Mortensen and Haas (2018) see teams as 'hubs', meaning "*centres of activities in which individuals connect in different ways as they contribute to that activity*".

Individuals each have their own perspective on whether they are member of a team themselves and which other individuals are members. In conceptualising team membership, Mortensen (2014) distinguishes three models of membership: formal membership (i.e. based on the official team roster, how the organization defines the team), identified membership (i.e. individuals who are labelled as team members by themselves or peers) and emergent membership (i.e. individuals whose patterns of interaction identify them as a team). Whilst the first model of membership focuses on the formal team boundaries defining membership, the latter two refer to informal boundaries, meaning the subjective perception of who is part of team. Following social identity theory, an individual's perception of being a member of a team is an important component of their identity. Individuals socially construct their environment by drawing boundaries around (groups of) people who contribute to their identity, defining their in-group and out-group. Also, individuals tend to categorize themselves into groups of people that share similar beliefs, goals, competences or knowledge (Lyubovnikova et al., 2014; Wimmer et al., 2019).

Different individuals can be certain on their team membership and agree on the membership of others. However, individuals can also disagree on who is member of a team and who is not when they base their own membership and those of others on different models of membership (Mortensen & Hinds, 2002). Also, each individual may change his/her definition of membership over time and across different situations. For example, individuals at the start of an organization may define membership based on the formal membership (i.e., the formal boundaries), but over time rely more on the emergent relations between individuals (Mortensen, 2014). Mortensen (2014) describes this phenomenon as the 'membership model divergence', defined as "*the misalignment among team members' models of who are, and who are not, team members*".

PATIENT INVOLVEMENT AND RELATED CONCEPTS

In addressing the role of patients in the team, the terms patient participation and patient involvement, but also patient empowerment and patient-centredness, are often used interchangeable. Though some research specifically addresses the distinction between these concepts, there appears to be little consensus on the conceptualisation of these concepts.

Both Cahill (1996) and Tambuyzer and colleagues (2014) link patient participation and patient involvement to the decision-making process, but have different perspectives on the level of active involvement of the patient in the decision-making process. Cahill (1996) sees patient participation as the bidirectional relationship between a professional and a patient, in which the information gap is narrowed and decision-making power is distributed so that

the patient can be an equal partner in the decision-making process. Though patient involvement also implies a relationship between a professional and patient, this relationship is more one-directional in which patients are more passive recipients of information (Cahill, 1996).

Tambuyzer and colleagues (2014) show in their literature review that active patient involvement in the decision-making process, instead of merely receiving information or being consulted, is one of the key defining elements of patient involvement. In their study, patient involvement is conceptualised by five key elements: (a) participation in the decision-making process about one's personal care, (b) active involvement, (c) involvement in a range of activities (e.g. having a voice in care plans, having access to suitable information), (d) the patient is an expert based on own lived experience and (e) there is a partnership between the patient and the care professional. In line with this conceptualisation of patient involvement, Castro and colleagues (2016) in their concept analysis of patient participation propose that patient participation should be defined as "*a patient's rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge"*.

Thompson (2007) discusses a taxonomy of patient-desired involvement, differentiating between 'patient-determined involvement' (i.e. the role patients want to have), 'professional-determined involvement' (i.e. representing how professionals want patients to act) and 'co-determined involvement' (i.e. match between the patient's desires and professional willing-ness towards involvement). Patient-determined involvement ranges from non-involvement to autonomous decision-making. Professional-determined involvement ranges from exclusion (i.e., the paternalistic perspective) to informed decision-making. Co-determined involvement is either dialogue or shared decision-making (Thompson, 2007).

In contrast to the above mentioned authors, Sahlsten and colleagues (2008) consider patient participation, in the context of nursing care, to be broader than merely related to the decision-making process. Also, their conceptualisation is more associated with the care professionals' perspective, focusing on the stimulating role that nurses need to have in patient participation. According to these authors, one of the defining attributes of patient participation is the transfer of power or control by the nurse to the patient. This entails that activities that are manageable for patients (e.g. self-care) are allocated to patients and nurses are supportive facilitators who empower patients. Throughout the nursing process, nurses need to invite, stimulate and support patients to perform activities themselves.

With regard to the concepts of patient empowerment and patient-centredness, Castro and colleagues (2016) have specifically focused in their concept analysis on these concepts in relation to the concept of patient participation. Patient empowerment is proposed to be defined as "the process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important". Patient-centredness focuses on the approach of care professionals to deliver care that is individualized, empowering and respectful. This implies that patients and care professionals share a relationship in which empathy, shared knowledge and mutual trust is present. Though the authors suggest that all concepts relate to the balance of power and control between care professionals and patient, patient empowerment is seen as a broader concept, in which active patient participation is an antecedent of empowerment. Also, patient participation can be seen as a way to achieve patient-centred care, which in turn can promote patient empowerment (Castro et al., 2016; Holmström & Röing, 2010).

Though the terms 'patient participation' and 'patient involvement' are thus commonly applied synonymously, throughout this thesis the term 'patient involvement' is used. In line with Cahill (1996) and Tambuyzer and colleagues (2014), the term patient involvement in this thesis refers to the role of elderly patients with multimorbidity in the decision-making process.

SELF-MANAGEMENT

With regard to the concept of self-management, the conceptualisation varies and is dependent on the context and perspective (Udlis, 2011). In this thesis, self-management is defined as *"the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a (chronic) condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life"* (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Through the process of patient empowerment, patients are facilitated by care professionals to self-manage their health situation (Anderson & Funnell, 2010).

Two concept analyses on self-management in the context of chronic illness have identified different antecedents of self-management (Udlis, 2011; Van de Velde et al., 2019). First, self-efficacy, referring to an individual's perception and confidence of his or her ability to perform an activity. This implies that chronically ill patients are able to deal with their chronic conditions and their consequences and have a positive way of coping with adversity. Second, patients need to be informed about their condition, the possible consequences and treatment options in order to be able to take responsibility over their conditions. Third, being able to self-manage your health entails being open to social support. Self-management does not exist in vacuum. Rather, (emotional) social support of among others family members and care professionals, is pivotal in self-management. Fourth, patients need to be active and take responsibility over the care process, for example by setting life goals. Fifth, self-management requires a reciprocal relationship between a patient and his/her care professionals, in which responsibilities and power are shared. Moreover, Van de Velde and colleagues (2019) in their concept analysis also specially address health literacy as an important antecedent of self-management, as low health literacy is shown to lead to poorer self-management behaviour.

In relation to the concepts of patient involvement and participation, Van de Velde and colleagues (2019) consider active patient participation in the care process, not merely in the decision-making process, an antecedent of self-management. Though Udlis (2011) in her concept analysis also acknowledges the importance of active participation, this is considered to be a dimension of self-management instead of an antecedent. Active patient participation implies that patients have an active attitude and are actively engaged in activities such as proper diet and keeping medical appointments. In this thesis, we underscore that self-management does not exist in vacuum and explore how the mutual relationships between elderly patients, their informal caregiver and primary care professionals influence patients' ability to deal with their chronic condition(s).

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CHAPTER 3

Professionals' perceptions of the conceptualisation of teams and the underlying factors: A mixed methods study

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ABSTRACT

Background: Due to the growing prevalence of elderly patients with multi-morbidity living at home, there is an increasing need for primary care professionals from different disciplinary backgrounds to collaborate as primary care teams. However, it is unclear how primary care professionals conceptualise teams and what underlying factors influence their perception of being part of a team. Our research question is: What are primary care professionals' perceptions of teams and team membership among primary care disciplines and what factors influence their perceptions?

Methods: We conducted a mixed-methods study in the Dutch primary care setting. First, a survey study of 152 professionals representing 12 primary care disciplines was conducted, focusing on their perceptions of which disciplines are part of the team and the degree of relational coordination between professionals from different disciplinary backgrounds. Subsequently, we conducted semi-structured interviews with 32 professionals representing 5 primary care disciplines to gain a deeper understanding of the underlying factors influencing their perceptions and the (mis)alignment between these perceptions.

Results: Misalignments were found between perceptions regarding which disciplines are members of the team and the relational coordination between disciplines. For example, general practitioners were viewed as part of the team by helping assistants, (district) nurses, occupational therapists and geriatric specialized practice nurses, whereas the general practitioners themselves only considered geriatric specialized practice nurses to be part of their team. Professionals perceive multidisciplinary primary care teams as having multiple inner and outer layers. Three factors influence their perception of being part of a team and acting accordingly: a) knowing the people you work with, b) the necessity for knowledge exchange and c) sharing a holistic view of caregiving.

Conclusion: Research and practice should take into account the misalignment between primary care professionals' perceptions of primary care teams, as our study notes variations in the conceptualisation of primary care teams. To enhance teamwork between professionals from different disciplinary backgrounds, professionals acknowledge the importance of three underlying conditions: team familiarity, regular and structured knowledge exchange between all professionals involved in the care process and realizing and believing in the added value for patients of working as a team.

INTRODUCTION

The number of elderly patients aged 65 years or older with multiple chronic conditions living at home is rapidly rising (Scherer et al., 2016; van Dongen et al., 2016). Research shows different high prevalence rates of elderly with multiple chronic conditions world-wide, ranging between 55% and 98% (Marengoni et al., 2011). Because of their high and complex needs, care for these patients is delivered by multiple primary care professionals from different disciplinary backgrounds (Bähler, Huber, Brüngger, & Reich, 2015; van Dongen et al., 2016). Strong collaboration between these professionals is important (Loeb, Bayliss, Candrian, & Binswanger, 2016), as it can lead to better patient outcomes in terms of patient-centred, high quality care and can improve not only patient satisfaction with care (Mulvale, Embrett, & Razavi, 2016; Trivedi et al., 2013), but also work satisfaction of professionals (Lemieux-Charles & McGuire, 2006).

In research, the concept of collaboration is often used as a general term to describe a range of collaborative structures (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005; Gilley & Kerno, 2010; Grumbach & Bodenheimer, 2004; Saltman et al., 2007). For example, a collaboration could consist of professionals with minimal interaction and no shared goal (Gilley & Kerno, 2010; Saltman et al., 2007). Members of these type of collaborations are more task focused and often feel little necessity for interpersonal contact (Saltman et al., 2007). This type of collaboration is often defined as a 'group' or 'network' (Gilley & Kerno, 2010; Saltman et al., 2007). A collaboration could also exist of members with a shared common goal, well defined tasks, task interdependency and stable membership (Tannenbaum, Mathieu, Salas, & Cohen, 2012). Historically, this type of collaboration is defined as a 'team' (Gilley & Kerno, 2010; Saltman et al., 2007). This type of collaboration et al., 2007).

In primary care, collaborations are often defined as 'primary care teams' (Lyubovnikova, West, Dawson, & Carter, 2014; West & Lyubovnikova, 2012; West & Lyubovnikova, 2013). Professionals from different disciplinary backgrounds can collaborate in formal structures, for example within the same organization, in which primary care teams are purposefully established, a common and shared care goal is set and professionals fulfil designated roles within the team. In such teams, accountability and procedural structures are embedded in the team, and the team membership of primary care professionals is clear (Saltman et al., 2007; Wageman, Gardner, & Mortensen, 2012).

However, in recent years, teams have tended to become more fluidly structured, operating within loose boundaries and accordingly leading to dynamic team membership (Bushe & Chu, 2011; Huckman & Staats, 2011; Mortensen, 2014; Mulvale et al., 2016; Summers, Humphrey, & Ferris, 2012; Tannenbaum et al., 2012; Wageman et al., 2012). Present-day teams are expected to continuously and rapidly adapt to changes and issues in their environment, for example to changing patient expectations and demands (Mickan & Rodger, 2000; Tannenbaum et al., 2012). Team membership has a dynamic nature (Tannenbaum

et al., 2012); therefore, professionals can be members of multiple teams at the same time (i.e., multiple team membership) (O'leary, Mortensen, & Woolley, 2011; Tannenbaum et al., 2012). Such teams are conceptualised as fluid entities in which membership is based more on task interdependency than formal structures (Saltman et al., 2007; Tannenbaum et al., 2012; Wageman et al., 2012). Fluid teams are often described as having an ad hoc or multi-layered structure (Tannenbaum et al., 2012; Wageman et al., 2012). In ad hoc teams, a team is built of members with diverse expertise to address specific needs, after which the team is dissolved and a new team is built (Huckman & Staats, 2011; Tannenbaum et al., 2012). Teams with multi-layered structures consist of multiple inner and outer layers. The inner layer is formed by members who have a central and permanent role in the team, whereas the outer layers consist of team members who are members for a limited time period during which their specific expertise is required (Humphrey, Morgeson, & Mannor, 2009; Tannenbaum et al., 2012).

Research on team fluidity shows both positive and negative effects of having dynamic team membership. By increasing the diversity of knowledge, team creativity and the opportunity for open discussions can be enhanced, which ultimately positively affects team performance (Choi & Thompson, 2005; Hirst, 2009). However, dynamic team membership can also lead to less coordination and team familiarity, as team members have less shared work experience (Mortensen, 2014; Summers et al., 2012). According to Mortensen (2014), dynamic team membership can lead to a misalignment of team members' perceptions regarding who is considered part of the team, which is referred to as the membership divergence phenomenon.

Although one could argue that the membership divergence phenomenon (Mortensen, 2014) may be an issue in the primary care setting due to the variety of conceptualisations of primary care teams, little research has focused on primary care professionals' perceptions of team membership (Jaruseviciene et al., 2013). Therefore, the basic questions regarding how primary care professionals conceptualise teams and whether they perceive themselves as working as a team with professionals from other disciplinary backgrounds remain unanswered. Due to the changing and more fluid structure of present-day teams, is it debatable whether the term 'team' is still the appropriate term to describe these type of collaborations (Wageman et al., 2012). Regardless of the structures or perceptions of the type of collaborations between primary care professionals, collaborations are frequently labelled as teams merely on the assumption that teamwork will lead to superior outcomes (Lyubovnikova et al., 2014; West & Lyubovnikova, 2013). This phenomenon is discussed by Allen and Hecht (2004) as the 'romance of teams'. However, if primary care professionals do not perceive themselves as working as a team, it may not result in superior outcomes and is more likely to negatively affect their collaboration and ultimately the quality of care (Saltman et al., 2007; Sargeant, Loney, & Murphy, 2008).

Research suggests different underlying factors that could influence professionals' perceptions of which disciplines they consider to be part of a team(Allen & Hecht, 2004; Choi & Thompson, 2005; Hirst, 2009; Humphrey et al., 2009; Jaruseviciene et al., 2013; Lemieux-Charles & McGuire, 2006; Mickan & Rodger, 2000; Mortensen, 2014; O'leary et al., 2011; Sargeant et al., 2008; Sheard & Kakabadse, 2002; Xyrichis & Lowton, 2008). These factors revolve around the presence of formal work processes within teams (e.g., communication, clearly defined goals and regular feedback loops to improve team performance) (Gucciardi, Espin, Morganti, & Dorado, 2016; Lemieux-Charles & McGuire, 2006; Mulvale et al., 2016; Xyrichis & Lowton, 2008) and informal social processes (e.g., mutual respect, trust and understanding of each other's roles) (Gucciardi et al., 2016; Mulvale et al., 2016; Sargeant et al., 2008; Sheard & Kakabadse, 2002).

The interrelation between formal and social processes in teams is described in the 'relational coordination' theory (Gittell, Weinberg, Pfefferle, & Bishop, 2008; Gittell, 2002) and is defined as "*a mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration*" (Gittell, 2002). This theory identifies key concepts regarding the communication and relationship ties between team members that underpin effective teamwork (Gittell, 2008). The quality of communication consists of four dimensions: frequency, timeliness, accuracy and a focus on problem solving rather than blaming (Gittell, 2006). The quality of relationships consists of three dimensions: the extent to which team members have shared goals, shared knowledge and mutual respect (Gittell, 2006). Although the relational coordination theory often focuses on the ties between core team members, Gittell (2011) pleas for an extension of the theory beyond the inner layer and to include relational coordination with non-core participants (i.e., the outer layers), as these participants may also play an important role in the work process (Tannenbaum et al., 2012). This approach emphasizes the importance of including a broad range of team structures and taking team fluidity into account.

Research on relational coordination suggests an interaction and mutually reinforcing effect between the degree of relational coordination and professionals' perceptions of team membership. On the one hand, relational coordination can positively affect the perception of team membership (Cramm & Nieboer, 2012a). Research shows that for primary care delivery, specifically disease-management programmes for chronically ill patients, higher degrees of relational coordination exist between professionals from different disciplinary backgrounds compared to professionals from the same disciplinary background (Cramm & Nieboer, 2012b). This could be explained by the emphasis of disease-management programmes on multidisciplinary interactions, as the effectiveness of chronic care delivery is dependent on the communication and relationships between professionals (Cramm & Nieboer, 2012b). Following this line of reasoning, we could say that professionals from different disciplinary backgrounds who share high degrees of relational coordination are more likely to perceive each other as members of the same team and to collaborate as a team. On the other hand, the degree of relational coordination between professionals could be enhanced by facilitating interactions between professionals in multidisciplinary meetings (Hartgerink, Cramm, Bakker, Eijsden et al., 2014a). This suggests that when professionals from different disciplinary backgrounds get the opportunity to meet each other, they are more likely to perceive each other as part of the same team, which could result in higher degrees of relational coordination.

In this study, the perceptions of primary care professionals from different disciplinary backgrounds are our central focus. We aim to provide more insight into the concept of primary care teams and the functioning of these teams from the perspective of primary care professionals themselves. Our research question is the following: 3What are primary care professionals' perceptions of teams and team membership among primary care disciplines and what factors influence their perceptions?

METHODS

In this paper, a sequential mixed-methods approach was used. First, a questionnaire survey study was conducted focusing on the perceived team membership and relational coordination between professionals from different backgrounds. The quantitative results showed a misalignment of the perceptions of professionals from different disciplinary backgrounds regarding which disciplines were part of the team. This analysis will be discussed in more depth in the results and discussion sections. Subsequently, semi-structured interviews with professionals representing different primary care disciplines were conducted to gain a deeper understanding of the misalignment and insight into the influencing factors.

Setting and participants

This study was performed in the primary care setting in the Netherlands. The Netherlands, comparable to other European countries such as the United Kingdom and Denmark, has been identified as having a strong primary care system with high access to primary care (Kringos, Boerma, Hutchinson, & Saltman, 2015; Kringos, D. et al., 2013). Similar to systems in Italy, Norway, Sweden and Estonia, primary care in the Netherlands is characterized by a referral system to secondary care and a gatekeeping position of general practitioners (Kringos. et al., 2013; Kringos, D. S., Boerma, Hutchinson, van der Zee, & Groenewegen, 2010). Although different professionals are considered to be primary care professionals, such as physiotherapists and pharmacists, general practitioners are seen as the central care providers and first contact persons in care for patients (Kringos et al., 2013). These professionals deal with a large range of health problems and diseases and patients need to obtain their referral to medical specialist care. Moreover, practice nurses play a more central role in care in countries such as the Netherlands, Poland and Sweden (Kringos et al., 2013). In the Netherlands, these nurses often provide health programs such as dietary programs to elderly and sometimes focus on a specific patient groups like diabetic patients (Kringos et al., 2013). In light of the growing aging population, many European countries such as the Netherlands, France and Germany emphasize 'ageing in place': treating patients at home for as long as possible (Triantafillou et al., 2010). From this viewpoint, these countries have restructured their health system with a decentralization of government responsibilities at local (municipality) level, focusing on strengthening the primary care system (Pavolini & Ranci, 2008; Triantafillou et al., 2010). With this decentralization, patients need to live independently at home for as long as possible and rely on their informal care network before applying for professional care provision (Triantafillou et al., 2010).

In this paper, we solely focus on the perceptions of primary care professionals and exclude social care and informal caregivers. Prior to the data collection for the questionnaire, the researchers composed a list of common primary care disciplines involved in care for chronically ill elderly patients based on existing research on primary care (table 3.1) (Wiegers, Hopman, Kringos, & Bakker, 2011). Convenience sampling was used to select participants. Managers of multiple types of primary care practices, for example primary care centres and monodisciplinary centres such as general practitioner centres, were approached by telephone or email.

X / X	
1. General Practitioners	7. (District) Nurses
2. General Practitioners Assistants	8. Helping Assistants
3. Physiotherapists	9. Primary Care Psychologists
4. Remedial Therapists	10. Geriatric Specialized Practice Nurses
5. Pharmacists	11. Occupational Therapists
6. Dieticians	12. Speech Therapists

Table 3.1. List of common primary care disciplines

The questionnaires were filled out anonymously. Informed consent was assumed by completion of the questionnaire. Participants were given two weeks to complete the questionnaire. After one week, a reminder was sent to all participants. The total sample consisted of 152 primary care professionals from 37 different primary care organisations (response rate of 38%). The participant characteristics can be found in table 3.2.

For the interviews, professionals from five main primary care disciplines were approached. In order to determine these five disciplines, we analysed our quantitative results and organized meetings with stakeholders in primary care. This approach resulted in the inclusion of the following disciplines: general practitioners, physiotherapists, occupational therapists and (district) nurses. During the interviews, multiple participants emphasized the importance of geriatric specialized practice nurses in elderly primary care. This discipline was therefore included as well. Convenience sampling and a snowball method were used to select participants. We conducted interviews until no new perspectives or underlying factors were being offered (i.e., saturation strategy), which finally resulted in 32 interviews.

Characteristic	Ν	%	
Sex			
Male	33	21.7	
Female	119	78.3	
Educational level completed			
Secondary school	13	8.6	
Secondary vocational	35	23	
Bachelor degree	89	58.6	
Master degree	14	9.2	
Other	1	0.7	
Discipline			
Physiotherapist	36	23.7	
Helping Assistant	31	20.4	
Remedial Therapist	22	14.5	
(District) Nurse	19	12.5	
General Practitioner Assistant	12	7.9	
General Practitioner	9	5.9	
Primary Care Dermatologist	6	3.9	
Geriatric Specialized Practice Nurse	5	3.3	
Dietician	5	3.3	
Occupational therapist	2	1.3	
Speech Therapist	2	1.3	
Primary Care Psychologist	2	1.3	
Other	1	0.7	
	Mean	SD	Range
Team tenure	6	7.2	1-35
Age (years)	40	12.1	21-64
Team size	9.9	5.4	2-40
Team diversity	0.46	0.30	0-0.93

Table 3.2. Quantitative survey: Participants characteristics (*n*=152)

Note. SD = Standard deviation

During the recruitment process of the participants as well as at the start of the interviews, all participants were repeatedly informed on the aims and purpose of the study. Informed consent was assumed by agreeing and completion of the interviews. Moreover, participants were repeatedly informed about the recording the interviews. At the start of each interview, the participants were explicitly asked for verbal consent for recording of the interviews. At all times, participants were allowed to withdraw their consent and end the interview. The participant characteristics can be found in table 3.3.

Variable	GP (<i>n</i> = 6)	Physiotherapist (<i>n</i> = 7)	Occupational therapist (<i>n</i> = 7)	(District) Nurse (<i>n</i> = 9)	Geriatric specialized practice nurse (<i>n</i> = 3)
Gender					
Male	2	2	0	1	0
Female	4	5	7	8	3
Age in years					
< 30	0	2	2	3	0
30 - 50	5	3	4	2	2
> 50	1	2	1	4	1
Work setting					
Home care organisation	0	0	0	9	0
General practitioner centre	2	0	0	0	2ª
Physiotherapy centre	0	3	0	0	0
Occupational therapy centre	0	0	5	0	0
Primary health care centre	4	4	2	0	1
Numbers of years practicing					
< 15	2	3	3	5	1
15 – 30	1	2	3	1	2
> 30	3	2	1	3	0

Table 3.3. Qualitative interviews: Participants characteristics (n = 32)

^a In the Netherlands, geriatric specialized practice nurses often work within general practitioners' centres

Quantitative questionnaire

The questionnaire was divided into two sections. The first section contained two questions on primary care professionals' perceptions regarding team membership, focusing on their perceived team size ("How many team members are on your team?") and team diversity ("Which of the following disciplines do you consider part of your team?"). Participants were asked to answer openly, without reference to their specific work setting or structure. For example, the general practitioners were asked to indicate which other primary care disciplines (as presented in Table 1) they considered part of their team. In the second section, the degree of relational coordination was assessed using a seven-item relational coordination scale. This scale was originally developed to measure airline operations (Gittell, Jody Hoffer, 2001) but has also been applied in health care settings (Gittell, Jody Hoffer et al., 2008). Sample questions include "How frequently do you communicate with each of these disciplines about a patient?" and "To what degree do people in these disciplines share your goals for the care of your patients?" A five-point Likert scale ranging from 1 ("never") to 5 ("always") was used. Participants were asked to answer the questions with respect to the other disciplines. For example, the physiotherapists were asked to score how frequently they communicated with the helping assistants about a patient. The used questionnaire can be found in appendix 1.

Principal component analyses revealed that the seven items loaded onto two factors with eigenvalues of 3.53 and 1.48, which explained 71.61% of the variance.

Qualitative interviews

The topic list for the semi-structured interviews was developed by the primary researcher and revised based on input from the full research team. The design of the topic list allowed an in-depth investigation of the underlying dimensions of the misalignment on team membership among professionals. Participants were first asked how they would define 'teams' and if they felt to be members of a team. Example questions include "What elements of teamwork could make you feel more like a member of a team?" and "What is important to you when collaborating with other disciplines?" The interview guide can be found in figure 3.1.

Quantitative analysis

The data were analysed using IBM SPSS 22.0. Descriptive statistics were used to analyse the sample characteristics, the perceived team size, and the relational coordination between disciplines. Each discipline's perceived team diversity was analysed using Blau's index for diversity (Blau, 1977). The index ranges between zero (completely homogeneous teams) and one (completely heterogeneous teams). To explore the different perceptions among disciplines regarding who is a member of the team, UCINET Software for Social Network Analysis was used to create a social network figure of the different disciplines. To analyse the relationship between perceptions regarding who is part of the team and the degree of relational coordination between disciplines, correlation analysis was performed.

Qualitative analysis

The interviews were audiotaped, transcribed verbatim and analysed using Atlas TI (version 7). Data analysis was a combination of inductive coding and deductive framework analysis and included several steps. First, the primary researcher read the transcripts multiple times to gain a preliminary understanding of the experiences of the participants. Then, the primary researcher initiated an open coding of all the data. Next, the full research team compared the codes to derived insights from literature on teams and team membership. Specific attention was paid to participants' conceptualisation of primary care teams and factors that participants mentioned that could increase their perception of being part of a primary care team. During this process, the codes found from the open coding process were grouped into subthemes, which were then grouped into major themes. For example, the codes 'flying in and out' and 'loose boundaries' were grouped into the subtheme 'team versus loose network', which was then included under the major theme 'conceptualisation of teams'. To ensure reliability, the themes were discussed among the full research team.

Part A: Introduction and consent

Part B: Description of the participant

Question	Follow up question(s)	Topics to discuss
Could you share some information about your professional background?		Disciplinary background, years active in the field, type of organisation
How are you involved in the care for elderly patients with chronic conditions?		Involvement in the for elderly patients with chronic conditions

Part C: Collaboration between professionals from different disciplinary backgrounds

Question	Follow up question(s)	Topics to discuss
Do you collaborate with professionals from other disciplinary backgrounds in the care for elderly patients with chronic conditions?	If answer is yes: a. Could you share something about what this collaboration entails?	Type of contact between professionals from different disciplinary backgrounds
How would you describe your own role in these collaborations?		Leadership, division of tasks
What are your feelings on how on well or not well the collaboration with other professionals currently is going?	a. What are positive elements of this collaboration?b. On which elements would you like to see improvement or change?	Opinion on the quality of collaborations between professionals from different disciplinary backgrounds
What is important to you when collaborating with other disciplines?		Crucial elements of collaborations
How do you communicate with these professionals regarding a patient's medical condition and care goals?		Type and frequency of contact and communication

Part D: Primary care teams

Question	Follow up question(s)	Topics to discuss
Often, collaborations are labelled as primary care teams. Do you feel to be part of a team?	a. Why (not)?	Sense of belonging to a team
How would you define a primary care team?		Definition and conceptualisation of a team
Do you find it important to work as a team with other professionals?		Added value of teamwork, willingness to work as a team
What elements of teamwork could make you feel more like a member of a team?		

RESULTS

Quantitative results

Who is part of the team?

The average indicated team size was 9.9 members and the average diversity in disciplines in the team was .46. When specifying team size per discipline (table 3.4), primary care dermatologists reported the largest team size (15 members), and primary care psychologists reported the smallest team size (7 members). Regarding team diversity, occupational therapists reported the highest diversity (.79), and remedial therapists reported the lowest diversity (.09).

Alignments and misalignments between the perceptions of professionals from different disciplinary backgrounds were found, as illustrated in figure 3.2. Notably, most arrows point towards physiotherapists, general practitioners, dieticians, helping assistants and (district) nurses, which indicates that these disciplines were most often considered to be part of the team. Helping assistants and (district) nurses consider each other to be part of their team; 89.5% of the helping assistants consider a (district) nurse to be part of their team and 81.1% vice versa. There is a maximum alignment of perceptions between general practitioners and geriatric specialized practice nurses, as both disciplines considered each other to be part of their team at a level of 100%.

Although general practitioners only considered geriatric specialized practice nurses to be part of their team, they were considered part of the team by three additional disciplines: helping assistants (45.2%), (district) nurses (42.1%) and occupational therapists (50%), indicating a misalignment in perceptions between general practitioners and these disciplines. Physiotherapists were considered to be part of the team by the remedial therapists (77.3%), speech therapists (100%), occupational therapists (100%) and (district) nurses (47.4%), whereas less than 40% of the physiotherapists considered any of these disciplines to be part of their team. Moreover, no arrows are present between physiotherapists and general practitioners or between general practitioners and dieticians, indicating that less than 40% of these disciplines to be part of their team.

Relational coordination

A (mis)alignment of perceptions was also found with regard to the perceived degrees of relational coordination. On a scale of one to five, shows the average degree of relational coordination between professionals from different disciplinary backgrounds, subdivided into the communication and relationship dimensions. Overall, the means scores on the communication dimensions are lower than those on the relationship dimensions.

Helping assistants and (district) nurses not only often perceive each other's discipline to be part of the team (figure 3.2), but also share roughly similar degrees of relational coordination on both dimensions. From the perspective of (district) nurses, the perceived degree of rela-

Tabl	e 3.4. Team size, diversity and part o	of the team												
In e	yes of:	team size	diversity	conside	red part of	f the team	(% yes)							
		mean	mean (SD)	1	2	3	4	Ś	6	7	8	6	10	11
	Total respondents group (n=159)	10,28	0,45 (0,31)	51,9	41,7	40,4	39,1	28,2	25,6	19,9	17,9	14,7	10,3	4,5
-	Physiotherapist (n=36)	9,18	0,44 (0,28)	94,4	25	27,8	19,4	11,1	41,7	30,6	38,9	30,6	8,3	0
2	(District) Nurse (n=19)	8,26	0,60 (0,21)	47,4	100	42,1	89,5	21,1	10,5	21,1	0	0	0	0
\mathcal{C}	General Practitioner (n=9)	10	0,64~(0,11)	11,1	0	88,9	0	88,9	11,1	0	33,3	0	0	0
4	Helping Assistant (n=31)	10,19	0,58 (0,28)	38,7	87,1	45,2	96,8	29	19,4	32,3	6,5	12,9	12,9	6,5
Ś	Geriatric Specialized Practice Nurse (n=5)	10,5	0,75 (0,10)	20	20	80	20	80	60	0	0	0	0	0
9	Dietician (n=5)	9,6	0,45 (0,14)	40	0	20	0	20	100	40	40	40	0	0
\sim	Occupational Therapist (n=2)	15	0,79 (0,09)	100	100	50	100	0	100	100	100	0	0	0
∞	Primary Care Psychologist (n=2)	7	0,36 (0,12)	100	50	0	0	0	0	0	100	0	0	0
6	Speech Therapist (n=2)	13,5	0,74 (0,13)	100	100	28,6	100	0	100	100	100	100	50	0
10	Remedial Therapist (n=22)	9,81	0,10 (0,20)	77,3	100	9,1	0	4,5	9,1	0	100	4,5	36,4	0
11	Primary Care Dermatologist (n=5)	15	(0) 0	0	0	0	0	0	0	0	0	0	0	83,3

tional coordination on the communication dimensions with helping assistants was 4.54, and the perceived degree of relational coordination on the relationship dimensions was 4.49. Vice versa, the perceived degree of relational coordination on the communication dimensions was 4.74 and on the relationship dimensions 4.78. Misalignments in the degrees of relational coordination were found for general practitioners. For example, from the perspective of (district) nurses, the perceived degree of relational coordination with general practitioners on the communication dimensions was 3.43 and on the relationship dimensions 3.64, while vice versa, the perceived degrees of relational coordination were 2.44 and 2.48, respectively.

Table 3.6 shows the correlation matrix between a specific discipline perceived to be part of the team and the perceived degree of relational coordination with that discipline, subdivided into the communication and relationship dimensions of the relational coordination theory. Overall, higher correlations were found between being perceived as part of the team and the



Figuur 3.2. Participants' perception of who is part of their team (percentages)

The arrows and percentages show which discipline and how manage participants (percentage) from a specific disciplinary background consider another discipline to be part of their team. For example, 77.3 percent of the remedial therapists consider a physiotherapist to be part of the team. The arrows represent percentages higher than 40 percent. The absence of an arrow implies a percentage lower than 40 percent. All percentages, also lower than 40 percent, are provided in table 3.4.

communication dimensions of relational coordination (i.e., frequency, timeliness, accuracy and a focus on problem solving rather than blaming), but the overall mean scores for the relationship dimensions were higher. Following the identified misalignment in perceptions as illustrated in figure 3.2 and table 3.5, the correlation matrix shows ambiguous relationships between a specific discipline considered to be part of the team and the perceived degree of relational coordination (i.e., communication and relationship) with that discipline. For general practitioners, there are relatively low correlations between perceiving that discipline to be part of the team and both the communication dimensions and the relationship dimensions (r = .35 and r = .17 respectively), although 40.9% of the participants considered general practitioners to be part of their team. Conversely, high correlations were found for primary care psychologists on both the communication dimensions and the relationship dimensions (r = .65 and r = .56 respectively), although only 18.8% of the participants considered this discipline to be part of their team. The (district) nurses and helping assistants showed high correlations on both the communication (r = .76 and r = .67 respectively) and relationship (r = .76 and r = .68 respectively) dimensions.

With discipline: Relational coordination in eyes of:	Physiotherapist	(District) Nurse	General Practitioner	Helping Assistant	Geriatric Specialized Practice nurse	Dietician	Remedial Therapist	Primary Care Dermatologist
Physiotherapist	3.68/ 3.94	2.74/ 2.96	2.95/ 3.64	2.81/ 3.03	2.04/ 2.50	2.46/ 2.74	1.83/ 1.96	1.19/ 1.26
(District) Nurse	2.85/ 3.08	4.54/ 4.61	3.43/ 3.64	4.54/ 4.49	2.88/ 3.27	2.52/ 2.61	1.45/ 1.47	1.41/ 1.72
General Practitioner	2.37/ 2.76	2.40/ 2.86	2.44/ 2.48	2.02/ 2.57	3.83/ 4.10	2.35/ 2.14	1.80/ 2.76	1.00/ 1.62
Helping Assistant	2.10/ 2.59	4.74/ 4.78	3.07/ 3.63	4.72/ 4.80	2.55/ 3.00	1.71/ 1.74	1.45/ 1.63	1.31/ 1.39
Geriatric Specialized Practice nurse	2.56/ 2.67	3.06/ 2.83	4.65/ 4.73	2.81/ 2.83	4.60/ 4.67	4.06/ 4.67	2.00/ 2.00	2.00/ 2.00
Dietician	1.60/ 2.20	1.00/ 1.00	3.50/ 3.87	1.25/ 1.27	2.78/ 2.87	2.63/ 2.53	1.00/ 1.00	1.00/ 1.00
Remedial Therapist	3.10/ 3.49	1.23/ 1.32	2.60/ 3.18	1.25/ 1.35	1.79/ 2.18	1.88/ 2.30	2.88/ 3.21	1.00/ 1.20
Primary Care Dermatologist	1.00/ 1.61	1.17/ 1.50	2.46/ 3.00	1.17/ 1.50	2.04/ 2.61	1.00/ 1.33	1.00/ 1.33	3.63/ 3.89
General Practitioner Assistant	1.55/ 2.09	1.75/ 1.95	4.36/ 4.75	1.70/ 2.11	3.65/ 4.51	1.67/ 2.45	1.14/ 1.36	1.00/ 1.39

Table 3.5. Mutual degrees of relational coordination, subdivided into communication and relationship dimensions

Mean score communication dimensions/mean score relationship dimensions

Groups lower than n=5 are eliminated

	Perceived as part of the team by all participants	Perceived degree of relation participants Communication dimensions		onal coordination by all		
				Relatio dimens	onship sions	
Discipline	%	Mean Correlation (r)		Mean	Correlation (r)	
General Practitioner	40.9	3.14	.35*	3.65	.17**	
Physiotherapist	54.4	2.71	.55*	3.10	.49*	
(District) Nurse	42.3	2.96	.76*	3.09	.67*	
Helping Assistant	39.6	2.94	.76*	3.10	.68*	
Practice Nurse***	29.5	2.58	.51*	2.99	.47*	
Dietician	26.8	2.17	.53*	2.39	.43*	
Remedial Therapist	10.7	1.73	.55*	1.95	.45*	
Occupational Therapist	20.8	2.05	.42*	2.37	.39*	
PC Dermatologist	4.7	1.30	.50*	1.47	.48*	
Pharmacist	16.8	2.00	.32*	2.36	.25*	
PC Psychologist	18.8	1.70	.65*	1.93	.56*	
Speech Therapist	15.5	1.65	.54*	1.87	.49*	

Table 3.6. Descriptives and correlations between perceived as part of the team and the degree of relational coordination

* Significant at .01 level

** Significant at .05 level

*** The category 'Practice Nurse' refers to the Geriatric Specialized Practice Nurses

Qualitative results

The aim of the interviews was to investigate the reasoning for the identified misalignment of the perceptions of primary care professionals regarding which other disciplines they consider to be part of their team. Analyses of these interviews showed two lines of reasoning. The first theme, 'conceptualisation of teams', focuses on the different perspectives of the participants regarding the concept of primary care teams. Second, our analysis identified three factors that could minimize the misalignment of perceptions: 'knowing the people you work with', 'the necessity for knowledge exchange' and 'sharing a holistic perspective of caregiving'. These three factors are combined in the theme 'factors influencing the perception of working as a team'. Specific quotes are included under each (sub) theme to provide meaning and context to the participants' perspectives.

Conceptualisation of teams

The first theme involved the meaning of the concept of teams. Most participants mentioned that teams consist of multiple layers. According to most of the general practitioners, the inner layer is formed by the general practitioners themselves, geriatric specialized practice nurses and (district) nurses, as these three disciplines are considered to have central tasks in caregiving and are involved for a long period of time. This contrasts the questionnaire

results, in which less than 40% of the general practitioners considered the (district) nurse part of the team. The outer circles are formed by professionals whose expertise is needed for a limited period of time. According to the general practitioners, these professionals are often physiotherapists and occupational therapists.

"A team to me is when together you provide high quality care for a patient. A network is more like loose grains of sand. A real team is often the general practitioners, the home care organization and the practice nurses. And occasionally, other people [KD: disciplines] are flown in like a physiotherapist or an occupational therapist. But the core of the team really is the general practitioner and the home care organization." (General practitioner 1)

"For example, an occupational therapist can arrange walkers for patients with Parkinson's. But long-term care, they don't provide that. They are more or less flown in, do their business and fly out again. And it could very well be that you need them again later, but not structurally." (General practitioner 2)

However, most occupational therapists and physiotherapists felt that in the eyes of patients, they do belong to the core of the team around a patient, as their fields of expertise focus more on helping a patient with daily activities than treating their medical condition. According to the occupational therapists, knowing how to manage daily life and how to remain independent are important goals for patients.

Which disciplines are considered by a professional to be part of the inner layer and the outer layer seem to be related to the extent to which professionals from different disciplinary backgrounds are familiar with each other and the frequency of contact. Some participants felt a lower "team familiarity" with professional who they do not meet or speak to on a regular basis. The importance of knowing the people you work with in relation to perceiving to work as a team is described more in depth in the second theme.

"Well, a social worker might be involved whom I have never spoken to or whose patient goals I might not know. That person will have a lower team familiarity towards me than the physiotherapist whom I regularly speak with regarding a client's condition. That may be via phone or email, that's not important to me. So, in that sense there are multiple layers." (Occupational therapist 1)

The extent to which participants felt that they were part of a team was divided and seemed to be related to the type of work structure (i.e., working within the same building or not). Professionals working within the same building often referred to each other as members of the same team. However, for professionals who work in a monodisciplinary centre, the team concept applies to professionals from the same disciplinary background.

"The centre I am currently working in does feel like a team, but actually, my team members are merely my fellow general practitioners." (General practitioner 3)

With regard to teamwork with professionals from other disciplinary backgrounds outside a formal structure or the same building, participants did not perceive to work as a team. These multidisciplinary collaborations were often described as "loose networks" around a single patient. The participants did not refer to these collaborations as teams because of the perceived incidental structure of the collaboration. Professionals who do not structurally work together for the same patient group are not perceived as a team.

"It [KD: collaboration with different disciplines] doesn't feel like a team because it's usually a one-time collaboration around a patient. And perhaps you meet the same people around another patient, but that doesn't make it a team. It's more an incidental collaboration around a patient. So, it's more like a network." (Occupational therapist 4)

Although most participants felt that all professionals ultimately want the best care for their patients, the participants felt that professionals work individually with few mutual connections.

"When I look at the care for the elderly that we give, I feel that the older person is at the centre and we as professionals stand around the patient. And everybody does their own thing. But it would be very nice if all of those professionals had connections with each other." (General practitioner 5)

Factors influencing the perception of working as team

The three most mentioned factors that could influence the perception of working as a team are described below.

Knowing the people you work with

Having met the other professionals in person and knowing who that person is could positively influence communication and coordination by increasing the levels of familiarity and trust. Professionals know what to expect from each other, know their mutual responsibilities and can hold each other accountable for their actions. The occupational therapists, physiotherapists and geriatric specialized practice nurses particularly emphasized the importance of knowing the other professionals involved in the care for the same patient.

"Well, there's a difference between knowing each other in the sense of 'I know the other person's name' and knowing in the sense of 'I ve seen his or her face'. If you recognize each other's faces, the collaboration will be ten times better because usually right after five minutes you'll know things like, 'Oh, everything will be all right with that physiotherapist', or 'Oh, that general practitioner is very involved'." (Occupational therapist 2)

"It does help a lot if you know each other. For example, the geriatric specialized nurse doesn't work in this building, but since you know each other, you've already seen each other, and together you've invested time in knowing each other's roles and expertise. You know what you can and can't expect from each other. Or you can sometimes think along with another professional. That works really well, and I also think it's important in elderly care." (Physiotherapist 1)

The general practitioners also acknowledged the positive effects of knowing the other professionals but mentioned a lack of time as a hindering factor. Additionally, the fact that multiple professionals represent the same discipline in care for the same patient was viewed as a barrier to getting to know each other. This was especially the case for (district) nurses working in the same home care organization, where multiple (district) nurses can be involved in the care for a single patient.

Knowing each other could not only benefit the professionals but also the patients. Participants felt that patient satisfaction and patients' trust in the care delivery could be increased if all of the professionals involved know each other and collaborate.

"What I notice with the elderly people whom I visit is that they like it very much when everyone involved in their care knows each other. For example, when I visit a patient, and they say "Yeah, my physiotherapist is M!", then I would say "Oh, I know her. I just saw her at another patient's home". "Oh, that's great!" So you can see that they like it when they know that you know the other professionals." (Occupational therapist 6)

The necessity for knowledge exchange

Some participants expressed their desire for regular multidisciplinary team meetings to discuss patient cases. However, a lack of time often hinders the organization of these meetings. Communication therefore usually takes place via email or phone. Both the frequency and the content of communication seem to be related to the degree of (task) interdependency between professionals and the patient's medical condition. Regarding the frequency of communication, all participants acknowledged that communication mostly occurs when the coordination of tasks is necessary regarding a patient's condition. When a patient is stable, communication is considered to be less necessary and thus less present. In that sense, communication is considered to be more incidental than structural.

"I think that everyone [KD: primary care professionals] is highly involved in the care for patients with multimorbidity, so there's no real necessity to have contact in any way. Look, as

far as I'm concerned, when things go really wrong, then there's a need to deliberate." (General practitioner 1)

As a side note, compared to the other disciplines, occupational therapists and physiotherapists found it more important to update the other disciplines on their tasks on a weekly basis, especially the general practitioners. These disciplines found it particularly important to keep the other disciplines informed, as they highly valued providing holistic care to patients. However, communication is often felt to be one directional; the general practitioners rarely respond to their emails.

Regarding the content of communication, participants found that information sharing solely focuses on a patient's medical condition; the professionals rarely communicate for personal (social) reasons. Some participants, particularly the occupational therapists and physiotherapists, expressed a desire for more proactive communication between disciplines to prevent further deterioration of a patient's condition. Instead of solely reacting to a patient's – deteriorating – condition, professionals should more proactively communicate with other disciplines when their expertise could be helpful. Some occupational therapists expressed a desire for professionals to focus on multidisciplinary patient goals and not solely focusing on patient goals within their own field of expertise.

"To me, it's important that other professionals know how to find me if they have any questions regarding my treatment of a patient. For example, that they inform me when they see a patient goal related to occupational therapy. And that they share important developments in their own fields of expertise with me. I currently feel that I share what I am doing more often, that as an occupational therapist, I see patient goals within the field of expertise of other disciplines and make these disciplines aware of these goals than the other way around. That happens sometimes." (Occupational therapist 4)

Sharing a holistic view of caregiving

Most participants felt that one of the core steps in enhancing teamwork is that each professional should have a holistic view of caregiving, meaning that professionals should not work individually and solely focus on the patient's needs within their own field of expertise, but should collectively try to address all of the patient's needs. Professionals should truly believe in the added value of working as a team around a patient instead of as distant individual professionals. As a result, they would actually want to work as a team. However, when professionals share little task interdependency, it can be difficult to see the added value of collaborating as a team, and they are therefore less likely to invest in teamwork. "It really also depends on your own perspective, whether you see each other as complementary and see each other's added value, or if you rather like to keep things to yourself." (Physiotherapist 7)

Some (district) nurses expressed a desire for more teamwork with general practitioners, but they felt that the general practitioners often prefer to work solo. The results from the general practitioners on this matter were mixed. Some expressed a wish for more teamwork between different disciplines on a regular and structured basis, while others felt that teamwork is only necessary on an incidental basis when a patient's condition is unstable.

"General practitioners always say, "we are so busy". Nobody else in the world is busy, but they are. If we work with a general practitioner, he visits a patient on his own time. He doesn't adapt to my schedule. It doesn't matter if I'm there or not. It makes me sad because sometimes the patient needs a bandage and he [KD: general practitioner] won't do it. We [KD: (district) nurses] are like a necessary evil. Nothing comes from the general practitioners that says that they're willing to collaborate. The love always needs to come from the other side." ((District) nurse 2)

DISCUSSION

Our study explored the perceptions of primary care professionals from different disciplinary backgrounds regarding the conceptualisation of teams and which disciplines they consider to be part of their team.

Conceptualisation of teams

Building further on the membership model divergence phenomenon of Mortensen (2014), our study first shows that for the complex primary care setting professionals from multiple disciplinary backgrounds have different perceptions of which disciplines are part of a primary care team. For example, (district) nurses frequently consider general practitioners to be part of the team, but the latter often do not consider (district) nurses to be part of their team.

This misalignment can be linked to how primary care professionals conceptualise teams. In line with the team fluidity literature (Tannenbaum et al., 2012; Wageman et al., 2012), our study shows that primary care teams are perceived to have a fluid nature and consist of multiple inner and outer layers. Primary care teams have an inner layer consisting of disciplines with long-term involvement in care and outer layers of disciplines who are only team members when necessary. However, primary care professionals perceive which disciplines are part of the inner or outer layers differently. To illustrate, our interview results show that general practitioners do not consider occupational therapists as part of their team, because

they help patients with specific problems and are only involved for a limited amount of time. However, the occupational therapists felt that they are part of the inner layer, giving their field of expertise to help patients with daily life activities.

Task interdependency is frequently mentioned as a core characteristic of teams (Kvarnström, 2008; Thylefors, Persson, & Hellström, 2005; Wageman, Hackman, & Lehman, 2005; West & Lyubovnikova, 2013) and has been shown to positively affect team processes and effectiveness (Lemieux-Charles & McGuire, 2006). This study emphasizes the importance of task interdependency in primary care teams and suggests that the extent to which professionals perceive other disciplines to be part of the inner or outer layers of the team is dependent on task interdependency. When task interdependency is low, the perceived need for professionals to communicate and interact with other professionals in order to achieve their goals is also low. Consequently, these professionals are more likely to consider each other as members of the outer layer of a team. Vice versa, when task interdependency is high, professionals are more likely to consider each other part of the inner layer of the team, and the perceived need for communication and knowledge exchange will be higher.

In addition, this study emphasizes the importance of the perceived goal interdependency, which refers to the interconnection among team members implied by the type of goal (individual or team) that guides their performance (Saavedra, Earley, & Van Dyne, 1993). Professionals who perceive patient care as a holistic process and acknowledge that achieving patient goals from their own discipline is dependent on patient goals from other disciplines, will be more likely to want to collaborate as a team and consider each other as team members.

Underlying factors

For certain combinations of professionals from different disciplinary backgrounds, the (mis) alignment of perceptions regarding which disciplines are part of the team seems to be related to the perceived degree of relational coordination. For example, (district) nurses and helping assistants not only frequently consider each other to be part of the team but also share high degrees of relational coordination. This result suggests that (district) nurses and helping assistants often perceive each other to be part of the inner layer of a team and likely share equal expectations regarding, for example, their roles and responsibilities, shared goals and the frequency of their communication. When focusing on general practitioners in relation to the other disciplines, the expectations do not always align. For example, general practitioners are perceive relatively high degrees of relational coordination with general practitioners on both dimensions. However, vice versa, only a small percentage of the general practitioners consider these two disciplines to be part of the team, and their perceived degrees of relational coordinations are relatively low.

In practice, general practitioners are often considered to have a central role in the caregiving process (Weenink, van Lieshout, Jung, & Wensing, 2011). Our study suggests that most primary care professionals acknowledge this central role of general practitioners, but that general practitioners do not always acknowledge the central role that other disciplines could play in the caregiving process. By having a highly medicalised focus on patient needs, some general practitioners tend to not perceive disciplines with a less medicalised contribution to patient care as part of the inner layer. However, these disciplines (e.g. occupational therapists) are crucial for patients' quality of life as they focus on daily life activities. Our study also indicates a lack of or little communication between general practitioners and other disciplines. Communication was often a one-way road towards general practitioners as they fail to respond to emails or phone calls. The misalignment in perceptions and lack of communication between general practitioners and other disciplines also suggests power differentials between the former and latter. Research shows that power can negatively affect team effectiveness (Lemieux-Charles & McGuire, 2006) and affects the strategic choices of care professionals whether to collaborate, with whom and to what level (McDonald, Jayasuriya, & Harris, 2012). Research by Rieck (2014) on the relationship between general practitioners and pharmacists shows that power distances exist between these disciplines and is based on knowledge and expertise differences. General practitioners had little trust in the expertise of the pharmacists and felt to perform tasks better independently than as a team with the pharmacists. Following this line of reasoning, we could say that in our study, power differentials between general practitioners and other disciplines exist. General practitioners felt little necessity to function as a team with especially disciplines with a less medicalised contribution to care. This lack of communication and teamwork could negatively influence the quality of delivered care (Hartgerink, Cramm, Bakker, Eijsden et al., 2014b).

Our study suggests three underlying factors of the misalignment in perceptions: 1) knowing the people you work with, 2) the necessity of knowledge exchange, and 3) sharing a holistic view of caregiving. These factors are related to the communication and relationships between primary care professionals and could contribute to enhancing their perception of being part of a team.

In line with other studies such as that of Gucciardi and colleagues (2016), our study emphasizes the importance of investing in communication and relationships between all professionals involved in the care for a single patient. Research has shown that high levels of trust, mutual respect and mutual understanding of each other's roles are important characteristics of effective teamwork (Gucciardi et al., 2016; Mulvale et al., 2016; Sargeant et al., 2008). Building further on other research (Gucciardi et al., 2016), the responses of our participants suggest that familiarity could increase mutual levels of trust, respect and understanding between professionals. By enabling primary care professionals from different disciplinary backgrounds to meet and get to know each other, trust, respect and understanding are nurtured. Furthermore, this study suggests that getting to know each other could also positively affect the quality of communication between professionals, as the professionals will be more familiar with each other.

Practice and research implications

To provide patient-centred holistic care to chronically ill elderly patients, all of the primary care professionals involved need to work together as one team, regardless of whether they perceive task interdependency. The importance of holistic care has often been emphasized in health policy, and our study shows that primary care professionals themselves acknowledge the need for a holistic view of caregiving. To provide holistic care, our study underscores the importance of strengthening the communication and relationships between professionals involved in the care for the same patient, as the professionals may have different expectations of each other.

In line with other research (Gittell, 2015; Gucciardi et al., 2016), we suggest that to improve team functioning, all professionals involved in the care for the same patient could benefit from meetings in which they have the opportunity to get to know each other and discuss their mutual roles, responsibilities and expectations. Research stresses the importance of informal contact between team members to enhance role clarification and social processes within the team (Gucciardi et al., 2016; King & Ross, 2004; Xyrichis & Lowton, 2008). By organizing these meetings, professionals can build on their mutual levels of trust, respect and understanding, and role conflict can be minimized. However, it is crucial that hindering factors such as a lack of time, motivation and the perceived added value of informal contact and engaging with each other are taken into account. This could for example be realised by not organizing specific meetings focused on informal contact, role clarification and engagement, but to integrate these elements into multidisciplinary team meetings in which critical incidents are discussed. For example, informal contact, role clarification and engagement could be integrated into simulation-based trainings at the workplace for professionals who already work together or need to communicate and coordinate their activities (Buljac-Samardzic, Dekker-van Doorn, van Wijngaarden, & van Wijk, 2010). Within these simulation trainings, professionals have the opportunity to re-enact a real-life case to stimulate and improve their teamwork around a patient (Buljac-Samardzic et al., 2010). Research has shown that simulation training improves technical skills as well as non-technical skills of professionals (Doumouras, Keshet, Nathens, Ahmed, & Hicks, 2012; Murphy, Curtis, & McCloughen, 2016; Tan, Pena, Altree, & Maddern, 2014). Further research is needed to gain more knowledge of underlying conditions that are necessary for these meetings to succeed.

Moreover, different researchers (Allen & Hecht, 2004; Lyubovnikova et al., 2014; West & Lyubovnikova, 2012; West & Lyubovnikova, 2013) have debated the definition of teams and have shown that the label "team" is often applied to a collaboration in the belief that teamwork leads to superior outcomes. Some research argues that in reality, many of these so-called teams consist of professionals who work individually, rarely communicate or do not share a common goal (Lyubovnikova et al., 2014; West & Lyubovnikova, 2013). Adding to this debate, this study shows that although a collaboration is frequently labelled as a primary care team, professionals from different disciplinary backgrounds often do not perceive

themselves as part of a team and have different perceptions regarding which disciplines are part of the team. Rather, some primary care professionals may perceive that they work on a team, while others may perceive that they work in a network. However, as our study shows that these networks are multi-layered, the actual structure and formal and social processes within networks may vary in different contexts. This also implies that researched primary care teams or primary care networks may vary in their actual structure and membership, making it difficult for example to compare primary care team effectiveness across studies. Thus, policy-makers, managers and researchers should carefully consider the specific context in which teamwork takes place and the perceptions of professionals on team membership and the conceptualisation of teams and networks. Our study shows that professionals may have different perceptions on team membership and task interdependency, frequency and content of communication between professionals varies. Therefore, when using the terms 'primary care team' or 'primary care network', it is important to specify who the members are and what their task interdependency and communication is.

Our study shows a misalignment in perceptions of primary care professionals and suggests different underlying factors influencing their perception. Further research is needed to more in depth explore this misalignment, for example by focusing on factors on a patient level. The extent to which professionals see each other as part of the inner or outer layer could be influenced by patient characteristics, such as complexity of patient condition, intensity of treatment and patient involvement.

Moreover, research on self-management and health care consultations underscores the importance of patient involvement and indicates that patients fulfil different roles, from passive recipients of care to active participants or co-producers of their care (Thompson, 2007). Therefore, future research on primary care teams should focus on the different roles of patients in the self-management of their diseases and on patients' team membership in primary care teams. In addition, because of the growing prevalence of informal caregivers and their unique role as semi-patients and semi-professionals (Weinberg, Lusenhop, Gittell, & Kautz, 2007), future research should also focus on informal caregivers' team membership.

Limitations

When interpreting our results, careful consideration must be paid to the following. First, due to our cross-sectional design, we cannot draw any conclusions regarding causality between the extent to which professionals perceive specific disciplines as part of their team and their perceived degree of relational coordination. At the same time, due to our mixed-methods design, our study does suggest that these concepts are related and that investing in communication and relationships between professionals is important for teamwork. Second, the quantitative component of our study included a moderate sample size and had an unequal distribution of participants per discipline. However, our sample included a large variety of

primary care professionals from different disciplinary backgrounds, reflecting the diversity of primary care services for chronically ill elderly patients.

Third, in both the quantitative and well as the qualitative component of our study we did not include all primary care disciplines from the same primary care practice, such as all members of one community care team, because we aimed to openly explore the relationships between professionals from different disciplinary backgrounds. We therefore cannot draw any conclusions on (mis)alignments of perceptions between professionals involved in the care for a specific patient. Future research could focus on exploring teams and networks around a specific patient and the perceptions of the professionals within these structures.

CONCLUSION

Our study shows that from the perspective of primary care professionals, the concept of primary care teams is ambiguous and misalignments exist regarding how these teams are conceptualised and which disciplines are perceived as part of the team. To create more alignment and to enhance professionals' perceptions of being part of a team, professionals emphasize the importance of knowing the people you work with, exchanging knowledge with all professionals involved and sharing a holistic view of caregiving. By focusing on these underlying conditions of teamwork, professionals are not only more likely to perceive themselves and professionals from other disciplines as team members but are also more likely to collaborate as a team.

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CHAPTER 4

The different perspectives of patients, informal caregivers and professionals on patient involvement in primary care teams. A qualitative study

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ABSTRACT

Background: Patient involvement in the decision-making process, especially for chronically ill elderly patients, has become an important element of patient-centred primary care in many countries, including the Netherlands. This study openly explores different perspectives of patients, informal caregivers and primary care professionals on patient involvement in primary care team interactions.

Methods: Sixty-four qualitative semi-structured interviews with chronically ill elderly patients, informal caregivers and primary care professionals from various disciplines. Underpinned by a phenomenology approach, this study used conventional content analysis for data analysis.

Results: Participants have different views of the roles of patients and informal caregivers in the primary care team and thus different expectations of the extent and level of patient involvement. Three challenges impact patient involvement in the team: (a) patients feel misunderstood and less involved that they would like when professionals take control, (b) patients have to balance the conflicting opinions of different professionals and (c) informal caregivers act undesirably as team leaders due to their own view of the level of patient involvement.

Discussion and conclusion: Patient involvement is formed in complex interactions between patients, informal caregivers and multiple professionals whose perspectives and expectations can be misaligned. Recognizing the value of patients and informal caregivers on the team could help professionals understand them better and thus limit the likelihood of challenges arising in team interactions.

INTRODUCTION

In the last two decades, health care has moved from a paternalistic professional-centred model toward a patient-centred care model that tailors care to patients' needs, values, and experiences (Oates, Weston, & Jordan, 2000; Pomey, Ghadiri, Karazivan, Fernandez, & Clavel, 2015; Stewart et al., 2003). Patient involvement, defined as "*enabling patients to take an active role in deciding about and planning their care*", is part of patient-centred care and increasingly pursued in many countries (Bovenkamp & Dwarswaard, 2017; Sheridan et al., 2015). The fast-growing literature on patient involvement in the decision-making process predominantly focuses on exploring factors that influence patient behaviour and active involvement (Davis, Jacklin, Sevdalis, & Vincent, 2007; Elwyn et al., 2001; Thompson, 2007).

The relational aspects of patient involvement are much discussed in the literature (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Davis et al., 2007; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009; Thompson, 2007). Davis and colleagues (2007) show that patient involvement is influenced by the way professionals interact with patients. Moreover, Smith and colleagues (2009) show how relatives and friends (i.e. informal caregivers) play a key role in patient involvement, for example by collecting information on the patient's behalf.

Building on such studies, this study contributes to the literature by exploring patient involvement in the decision-making process during interactions between patients, informal caregivers and primary care professionals in primary care teams. From this perspective, patient involvement is not a clear-cut concept, rather, it is co-produced through dialogue and interaction by patients, informal caregivers and professionals in their reciprocal relationships on the primary care team (Thompson, 2007). This makes it important to focus on patient involvement *within* primary care teams.

The patient can be seen as the single binding factor of the primary care team, as actual care delivery should depend on a patient's specific wishes and needs (Doekhie, Buljac-Samardzic, Strating, & Paauwe, 2017; LaDonna et al., 2016). Various patient involvement models see the patient as an expert with experiential knowledge of their own condition that could complement the knowledge of professionals (Bagchus, Dedding, & Bunders, 2015; Dongen, Habets, Beurskens, & Bokhoven, 2017; Pomey et al., 2015). Both patients and professionals often rely heavily on informal care (Bonsang, 2009; Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016; Weinberg, Lusenhop, Gittell, & Kautz, 2007; Wolff, Clayman, Rabins, Cook, & Roter, 2015). Informal caregivers (i.e. usually close family) are important members of the patient's support system who can provide emotional and everyday illness-related support (Rogers et al., 2016). However, in some cases they can also hinder patient involvement, by being overprotective or offering more than the patient desires (Gallant, Spitze, & Prohaska, 2007). Regarding patients and informal caregivers as valid members of

the team alongside professionals may contribute to delivering higher quality care (Dongen et al., 2017). However, many professionals do not regard the patient or informal caregiver as full team members and ignore their vital knowledge (Dongen et al., 2017; LaDonna et al., 2016). Thus, patients and informal caregivers sometimes feel left out or unheard (Sheridan et al., 2015; van Dongen et al., 2017).

Focus and aim of the study

This study focuses on patient involvement in the decision-making process for chronically ill elderly patients. Given the rapidly rising prevalence of these patients, their involvement is found to be particularly important (Bastiaens et al., 2007; Bodenheimer, Lorig, Holman, & Grumbach, 2002). Usually needing long-term care, elderly patients are often supported by informal caregivers as well as primary care professionals, which leads to frequent interactions between patients, informal caregivers and multiple professionals from different disciplinary backgrounds (Bonsang, 2009; Doekhie et al., 2017).

The study focuses not just on one perspective (e.g. the patient) as is often the case in the literature (Dongen et al., 2017; Dwarswaard, Bakker, Staa, & Boeije, 2016; Sheridan et al., 2015). Instead, we analyse the perspectives of all three actors (i.e. patients, informal caregivers and professionals) on their interactions by not merely examining patient-professional or patient-informal caregiver interactions as have been studied before (Bastiaens et al., 2007; Edwards, Davies, & Edwards, 2009; Gallant et al., 2007; Thompson, 2007; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). We also explore the influence of interactions among multiple professionals from different disciplinary backgrounds and among multiple informal caregivers on patient involvement.

Thus, the aim of this study is to openly explore the perspectives of patients, informal caregivers and primary care professionals on patient involvement in the decision-making process in primary care team interactions. Our research question is: *What are the perspectives of patients, informal caregivers and primary care professionals on patient involvement in the decision-making process in primary care teams?* It is important to expand the knowledge on the relational elements influencing patient involvement, and the insights gained from this study could be applied to further improve patient involvement interventions in the future.

METHODS

Study design

We conducted qualitative interviews to collect the data. Given the aim, a phenomenology approach allowed us to gain a deeper understanding of the subjective experiences of patients, informal caregivers and professionals with patient involvement in primary care teams within their own 'life-world', meaning the interactions between patients, informal caregivers and
professionals (Korstjens & Moser, 2017). We followed the consolidated criteria for reporting qualitative studies (COREQ) (table 4.1) (Tong, Sainsbury, & Craig, 2007).

No	item	Description					
Do	Domain 1. Research team and reflexivity						
1.	Interviewer/facilitator	K.D. (first author) conducted all the interviews					
2.	Credentials	KD was a PhD student, Master of Science (MSc) in Health Care Management and Master in Law (LL.M) in Health Care Law. MS, MBS, HB and JP have a PhD					
3.	Occupation	KD is working as a PhD student at the Erasmus School of Health Policy and Management (ESHPM), Erasmus University Rotterdam, the Netherlands. MS,MBS and HB are working as senior researchers at the ESHPM. JP is a professor at ESHPM and at Tilburg University, the Netherlands					
4.	Gender	KD, MS, MBS and HB are female. JP is male					
5.	Experience and training	The main researcher KD had experience in quantitative and qualitative research. She received two Masters degrees from the Erasmus University Rotterdam, the Netherlands. In addition, she underwent additional formal PhD education in qualitative research					
Rel	lationship with participants						
6.	Relationship established	There was no relationship between the researcher/interviewer with the patients, informal caregivers and 32 of the professionals. There was a relationship with six of the professionals. The researcher met these professionals during academic conferences or they were introduced to the primary researcher by colleagues of the research department for the purpose of this research project					
7.	Participant knowledge of the interviewer	The participants got the information that the interviewer was from the Erasmus University and that the research project was part of her PhD research. Also, the participants were given the information that the aim of the research was to gain more insight into their perspectives of what patient involvement is and how patient involvement is part of their daily interactions (with patients, informal caregivers and/or primary care professionals). When the participants asked, KD told more about her background as a researcher					
8.	Interviewer characteristics	The main interest of KD in the topic was based on previous research on the conceptualisation of primary care teams and the heterogeneity of chronically elderly patients regarding their needs and wishes in their care					
Do	main 2: Study design						
The	eoretical framework						
9.	Methodological orientation and Theory	The underlying research paradigm for this study was phenomenology. In phenomenology, researchers are focused the "lifeworld" of					

Table 4.1. Report on the accordance with the COREQ checklist for reporting on qualitative results

Ine underlying research paradigm for this study was phenomenology. In phenomenology, researchers are focused the "life--world" of individuals. In this study, we explored the daily life of and interactions between patients, informal caregivers and primary care professionals. Conventional content analysis was used for data analysis

No item	Description
Participant selection	
10. Sampling	Convenience sampling and a snowball method were used. The participants were geographically spread across the Netherlands. The sampling method is explained in the article. All approached participants agreed to participate
11. Method of approach	In the convenience sampling phase, the six professionals were approached via telephone or email. The professionals were asked for contact details of other professionals suitable for this study. All professionals were asked whether they knew patients and/or informal caregivers who would be suitable for this study. The professionals were also given an information letter to give to the patients and/ or informal caregivers. The contact details of the patients and/or informal caregivers were given by the professionals to the researcher by phone or email. The patients and informal caregivers were then approached by phone or email to set up an interview date
12. Sample size	In total, 64 interviews were conducted: 19 patients, 10 informal caregivers and 38 primary care professionals, The 38 professionals were 6 general practitioners, 7 physiotherapists, 15 (district) nurses, 7 occupational therapists and 3 geriatric specialized practice nurses
13. Nonparticipation	No participants withdrew from the study
Setting	
14. Setting of data collection	The interviews took place at a participant's preferred location. For the patients and informal caregivers, this location was their home. For the professionals the preferred location was their workplace
15. Presence of nonparticipants	At the interviews with three patients (patients 1, 2 and 13), their informal caregiver was also present. During the other interviews, no one else was present beside the participant and the researcher
16. Description of the sample	The participants' characteristics are described in tables 4.2, 4.3 and 4.4.
Data collection	
17. Interview guide	A topic list was used during the questions. Some of the questions of the topic list are given in table 4.5. Because of the semistructured nature of the interview, the topic list was used to give guidance to the interviews but was not binding for the content of the interviews. The topic list was adjusted throughout the interviewing phase of the research
18. Repeat interviews	No repeated interviews were carried out with the participants. Regarding the patients, this was because of their age and multimorbidity. Regarding the informal caregivers and professionals, time constraints of the participant and a long distance between the participant and the researcher were the reasons for no repeated interviews
19. Audio/visual recordings	All interviews were audio recorded with consent of the participants. The recordings were stored at the first authors' computer (KD) according to rules and regulations on data management of the Erasmus University Rotterdam

Table 4.1. Report on th	e accordance with the COREQ checklist for	or reporting on o	qualitative results	(continued)
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No item	Description
20. Field notes	KD made field notes during and after the interviews. These notes included observations and impressions that were not recorded such as nonverbal communication of the participant. Field notes were used in the analysis of the results
21. Duration	The duration of the interviews varied between 40 min and 1.5 h
22. Data saturation	Data saturation was discussed in the research team and reached for the interviews with the participants
23. Transcripts returned	Due to several practical reasons (old age of the patients and/or informal caregivers, time constraints of the participants, no possibility to use Internet connection), the transcripts were not returned to the participants for comments
Domain 3: Analysis and findings	
Data analysis	
24. Number of data coders	The first author performed the open coding of the data. The whole research team participated in the axial and selective coding process. Information on the coding of the data is provided in the method section of the article
25. Description of the coding tree	No coding tree was used. The themes were derived from the data as we used conventional content analysis for data analysis
26. Derivation of themes	The themes were derived from the data and were discussed and agreed on by all the authors
27. Software	Atlas TI program was used for the coding and analysis of the data
28. Participant checking	Due to practical reasons as explained at number 23, there was no feedback of the participants on our findings. During the interviews, the researcher repeated and summarized the answer of the participant to ask for clarifications and confirmation of the interpretation of the researcher of the answers. At the end of the interview, the researcher gave a short summary of the interview content to ensure the researcher did understand the main content right
Reporting	
29. Quotations present	The themes in the result section are illustrated by participant quotations. Each quotation is identified by a participant number. The participant numbers do not correspond with the numbers in tables 4.2, 4.3 and 4.4 to ensure the anonymity of the participants
30. Data and findings consistent	To our point of view, the presented data and findings are consistent
31. Clarity of the major themes	The major themes are present in the result section of the article. Each theme is given a different heading
32. Clarity of the minor themes	Minor themes are described in the result section and addressed as subthemes of the major themes

Table 4.1. Report on the accordance with the COREQ checklist for reporting on qualitative results (continued)

This study defines primary care teams as a platform of interaction between patients, informal caregivers and primary care professionals. Research shows that various primary care professionals become team members depending on the course of the patient's illness and suggests that patients and informal caregivers should also be seen as team members (Doekhie et al., 2017; Rogers et al., 2016; Weenink, van Lieshout, Jung, & Wensing, 2011). We did not examine teams as a whole (i.e. one specific patient, his/her informal caregiver and all professionals involved). Rather, we aimed to openly explore the perspectives of the potential "team members" and thus selected interviewees within one of the three participant groups. The elderly are defined as aged 60 years or older in correspondence with the World Report on Ageing and Health of the World Health Organization (World Health Organization, 2015). We conducted in total 64 interviews with elderly patients (n=19), informal caregivers (n=10) and primary care professionals (n=38) who were: general practitioners (n=6), physiotherapists (n=7), (district) nurses (n=15), occupational therapists (n=7) and geriatric specialized practice nurses (n=3). Tables 4.2, 4.3 and 4.4 provide details of the participants.

Our study protocol (No. MEC-2017-207) was reviewed by the medical ethics committee of the Erasmus Centre, Rotterdam, the Netherlands. The Medical Research Involving Subjects Act did not apply, so the committee waived further examination.

Data collection

The first author (i.e. KD; primary researcher) collected the data. Prior to the study, the researcher had no established relationships with the participating patients, informal caregivers and 32 of the 38 primary professionals. First, convenience sampling was used to select six professionals. Selection criteria were (1) working as one of the five types of primary care professionals (listed above) and (2) involved in caring for chronically ill elderly. The primary researcher first approached six professionals in her own network (i.e. from previous research projects or introduced by a colleague researcher) via email or telephone. Then, a snowball method was used. That is, during the interviews with these six, the researcher asked for the contact details of other professionals who would be suitable to take part in this study. These 32 professionals were invited to be interviewed via telephone and email and all agreed. At the interviews, the professionals were given a letter about the purpose of the study to pass on to patients and informal caregivers who would also be suitable for this study, asking for their consent to be contacted by the researchers. Subsequently the people who consented were approached by telephone or email and all agreed to take part. Interviews lasted until no new insights were offered (i.e. data saturation).

Interviews and study procedure

The interviews took place at the participant's preferred location and lasted between 40-90 minutes. The informal caregiver of patients 1, 2 and 13 was also present during the interview. The interview began with the researcher introducing herself to the participant, explaining

	Age	Gender	Chronic condition(s)	Informal caregiver	Most involved primary care professionals
Patients					
1	62	Male	Paraplegic, hearing disability	Spouse	GP, (district) nurse
2	68	Female	COPD, physical limitations due to stroke	Daughter	GP, physiotherapist, (district) nurse
3	75	Female	COPD, Parkinson's disease	Spouse	GP, physiotherapist, (district) nurse
4	77	Male	Prostate cancer, limitations due to stroke	Spouse	GP, geriatric specialized practice nurse, physiotherapist, (district) nurse
5	77	Female	Stroke, rheumatic disease, heart failure	Daughter	GP, occupational therapist, (district) nurse
6	77	Female	Cardiovascular disease, rheumatic disease	Daughter	GP, physiotherapist (district) nurse
7	77	Female	Asthma, hearing disability, Parkinson's disease	Spouse	GP, physiotherapist, (district) nurse
8	78	Female	Cardiovascular disease, osteoporosis, arthritis	Friend	GP, physiotherapist, (district) nurse
9	81	Female	Asthma, hearing disability	Daughter	GP, (district) nurse
10	82	Female	Parkinson's disease, vision problems	Daughter	GP, physiotherapist, occupational therapist, (district) nurse
11	83	Female	Asthma, rheumatic disease	Son	GP, geriatric specialized nurse, (district) nurse
12	85	Female	Arthritis, limitations due to stroke	Son and daughter	GP, occupational therapist, (district) nurse
13	85	Male	Stroke, arthritis, hypertension	Daughter	GP, physiotherapist, (district) nurse
14	87	Female	Osteoporosis, heart failure	Daughter	GP, occupational therapist, physiotherapist, (district) nurse
15	89	Male	Limitations due to heart attack, vision problems	Spouse	GP; physiotherapist; (district) nurse
16	89	Female	Rheumatic disease	Daughter	GP, physiotherapist, (district) nurse
17	90	Female	Diabetes, heart failure	Granddaughter	GP, geriatric specialized practice nurse, physiotherapist, (district) nurse
18	91	Female	Multiple sclerosis, hearing disability, vision problems	Spouse	GP, occupational therapist, (district) nurse
19	98	Female	Heart failure; vision problems	Daughter	GP, (district) nurse

Table 4.2. Characteristics of patients (*n* = 19)

GP = general practitioner

the reasons for doing the research and asking for explicit verbal consent to audio record their conversation. Informed consent was assumed by participants' agreement and completion of the interview. All participants gave permission to use quotations from the interviews anonymously. At any time, respondents were allowed to withdraw their consent and end the interview. None withdrew their consent.

	Age	Gender	Relationship to patient
Informal caregivers			
1	57	Female	Daughter
2	60	Male	Daughter
3	65	Female	Spouse
4	71	Female	Spouse
5	73	Female	Spouse
6	75	Male	Spouse
7	77	Male	Spouse
8	77	Male	Spouse
9	79	Male	Spouse
10	87	Male	Spouse

Table 4.3. Characteristics of informal caregivers (*n* = 10)

The semi-structured interviews were conducted in person. The primary researcher developed the topic lists and interview guides and revised these following inputs from the entire research team. The interviews focused on the interactions in primary care teams and covered three main topics: (a) participants' perspectives on primary care teams and team membership (b) differences in the nature and level of involvement in the team and (c) the role of professionals and informal caregivers in stimulating or hindering patient involvement in the team. All the participants were invited to illustrate their answers from real-life situations. Table 4.5 provides a selection of questions asked in the interviews.

Data analysis

The interviews were transcribed verbatim and analysed with Atlas TI. Given the explorative nature of this study, conventional content analysis was used, with the themes derived from the data and not based on preconceived categories or theoretical perspectives (Hsieh & Shannon, 2005). KD first openly coded the data, whereupon MS, MBS, HB and JP and KD (i.e. the whole research team) performed axial coding, grouping comparable codes into one code. For example, the codes 'hesitant to speak up to a professional' and 'difficulties sharing feelings with a professional' were grouped together under 'patient's ability to speak to professionals'. Then, the research team discussed the codebook and performed selective coding, which led to two major themes: (1) who is considered part of the team and (2) challenges in the team that (could) impact patient involvement.

Trustworthiness

Several steps were undertaken to comply with the five quality criteria for trustworthiness of qualitative research (i.e. credibility, transferability, dependability, confirmability and reflexivity) (Korstjens & Moser, 2018). To enhance the credibility of the results, participants were

	Age	Gender	Number of years as professional employment
General practitioners			
1	34	Female	3
2	40	Female	15
3	43	Male	10
4	44	Female	16
5	57	Female	35
6	58	Male	32
Physiotherapists			
1	24	Female	1.5
2	31	Female	9
3	34	Male	34
4	37	Female	20
5	41	Male	14
6	51	Female	30
7	63	Female	39
(District) nurses			
1	23	Female	2
2	27	Female	2
3	29	Female	4
4	32	Female	16
5	33	Female	10
6	34	Female	12
7	42	Female	15
8	46	Female	12
9	46	Female	17
10	54	Female	16
11	55	Female	33
12	55	Female	30
13	55	Female	16
14	55	Female	30
15	57	Male	35
Occupational therapists			
1	25	Female	1
2	28	Female	4
3	32	Female	10
4	34	Female	16
5	35	Female	16
6	36	Female	17
7	62	Female	41
Geriatric specialized practice nurses			
3	40	Female	8
1	41	Female	10
2	59	Female	13

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	Questions		
Topics	Patients	Informal caregivers	Primary care professionals
1. Participants' perspectives on primary care teams and team membership	a) Please describe the people involved in your care process	a) What does the word 'primary care team' mean to you?	a) What does a primary care team mean to you?
	b) What activities do you do to benefit your health?	b) Who do you consider to be part of the primary care team of your family member?	b) Please list who you consider a member of your primary care team?
2. Differences in the nature and level of involvement between patients	a) Please describe how decisions concerning your health are usually made.	a) How well can your family member make decisions about their own treatment?	a) Have you come across any differences in the level of patient involvement and if so, what kind?
	b) Have you ever disagreed with a family member or professional on your care team? If so, what did you do?	b) How well can your family member fully understand their health situation?	b) Please give examples of (1) a patient highly involved in their care process and (2) a patient not involved in the process.
3. The role of professionals and informal caregivers in stimulating or hindering patient involvement	a) What do you find important in the care you receive from this person [professional or informal caregiver]?	a) How would you describe your own role in looking after your family member?	a) How would you describe your professional role in stimulating patient involvement?
	b) Is there anything you wish was different in the way you receive care from this/these person/s?	b) How would you describe the interaction or relationship with [a professional]?	

Table 4.5. Main interview topics and questions

explicitly encouraged to back their views with concrete examples. Follow-up questions were asked to explore the context of examples and enrichen the data (i.e. prolonged engagement) (Korstjens & Moser, 2018). We used investigator triangulation, meaning that all the authors of the study discussed the axial and selective coding process as well as the analysis and interpretation of the data (Korstjens & Moser, 2018). Regarding the transferability of the results, the thick description used where appropriate in the results section provides more insight into the specific context (Korstjens & Moser, 2018). For example, some results specifically apply to elderly patients with deteriorating cognitive abilities; this is made clear. Regarding to the dependability and confirmability of the results, KD made an audit trail, which described in detail all the steps undertaken from the start of the project to the reporting of the findings (Korstjens & Moser, 2018). Last, to enhance reflexivity, KD kept a diary on the conceptual lens, the assumptions and preconceptions of the researchers and how these could affect the phases of the research project (Korstjens & Moser, 2018). The whole research team frequently discussed this diary during data analysis meetings.

RESULTS

Here we first report on the participants' ideas on team membership and what their role in the team is or should be. Next, we explore the various perspectives and expectations of the latter that can cause challenges within the team.

Who is considered part of the team?

Overall, the position and role of professionals was not contested, whereas the respondents did have diverging perspectives on the role and position of patients and informal caregivers. No patients or informal caregivers specifically mentioned either themselves or the other as part of the team. Corresponding with the professionals' view, teams were described in terms of a professional collaboration. Especially physiotherapists and occupational therapists saw involving patients as an essential element of their work. Patient involvement was described as "*placing patients and their wishes central in the care process*", or "*letting patients make their own decisions*". The views of professionals differ on whether such involvement implies that patients actually play a role *on* the team: some professionals feel that patients are team members while others acknowledge the importance of focusing on a patient's desires but still place the patient outside the team.

"I don't believe that patients have a very big role. Well, it is big, in the sense that a patient's questions, care needs, wishes and limitations are the starting point, but after all that is clear, you only consult with your [primary care] team. And afterwards, you report the outcome back to the patient" (Occupational therapist 1).

Some professionals do consider informal caregivers a part of the team. Geriatric specialized practice nurses and occupational therapists see informal caregivers as key persons in the care process, often providing emotional support to patients, encouraging self-management and taking over care tasks. Though none of the informal caregivers specifically identified themselves as team members, the majority expressed feeling highly involved in the care process and emphasised their close connection with the professionals who frequently ask them for help. This applies particularly to participants who have been informal caregivers for a number of years.

"I think they [the nurses] feel that I fit in with them. I've been an informal caregiver for so long and I do so many things. I think they see me as one of them. So our relationship is very good. They also tell me things about their personal situation. It's a bit like family" (Informal caregiver 1). A majority of the patients expect the general practitioner to lead the team. The older general practitioners particularly (i.e. 50 years or older) share this view and feel that they need to take on a steering role.

"I think the older generation does not feel the need to have a clear leading role in the sense of I want to be involved in the entire process'. It's more like, 'If you say so, doctor, we will do that'. And of course, you will discuss the important things. But overall, we are pretty steering" (General Practitioner 1).

Though professionals do not explicitly mention the patient as part of the team, most believe that in an ideal world patients should take a leading role in their own care process. Patients should take responsibility for their own health and only consult professionals when necessary. When patients are unable or unwilling to fulfil this role, many professionals view the informal caregiver as a proxy for the patient and expect them to step in and take the lead. Most informal caregivers try hard to involve their family member, even if he or she is less capable of fully understanding their situation. For example, some informal caregivers always have their family member join a meeting with professionals, even if their family member is not able to engage actively and the informal caregiver needs to take the lead.

Challenges in the team that could impact patient involvement

Our findings reveal that when ideas on the team positions and role divisions do not align, challenges can arise. These challenges impact patient involvement and the role patients can or are willing to play in their care. In the following sections, we discuss these challenges.

Patients as active participants or passive bystanders

First, when professionals consider themselves the central figure in the team, this can negatively impact their relationship with those patients who want to play a more active role. Some patients feel limited in taking on an active role because of their interactions with professionals. They feel treated like passive bystanders in their own care process and that the professionals make decisions *for* them instead of *with* them. These patients want to be actively involved and feel obliged to express this explicitly.

"The experts talk about you as if you're not even there. I always think that you should be assertive. You should tell them, like 'hey, listen up, you know, you're talking about me" (Patient 1).

Other patients want to express their own opinions and wishes but hesitate to do so because of possible negative reactions. Patients sometimes feel that professionals do not always value their opinion, while in some situations, they feel they know best. Most occupational therapists and physiotherapists say that is it important to encourage patients to express their wishes and make sure that the patients' wishes are the starting point of the caregiving process. However, some of these professionals tend to fall into a "repair-reflex" mode, immediately coming up with what they think is the best solution for a patient's problem without asking the patient what he or she believes would be best.

"I think we [professionals] should say 'Oh, I can fix that for you' less often. I tend to do it and sometimes realize that I am patronizing them [patients]. I shouldn't. Caregivers should be more aware of this. I think that professionals today are very comfortable fixing things for people" (Geriatric specialized practice nurse 1).

Conflicting ideas amongst professionals in the team

Second, the various professionals on the team can have conflicting ideas about the desirable level of patient involvement and their role in stimulating it. They can have diverging expectations of how professionals from other disciplinary backgrounds should act in the best interests of the patient. For example, some physiotherapists feel that helping assistants from home care organizations tend to 'over help' patients, whilst physiotherapists strive to activate patients to a maximum.

"A home care nurse puts the food in the microwave, brings it to the table and sets it in front of the patient. These people mean well and give lots of tender loving care. But I tell them [home care assistants]: 'Let them [patients] get their own food out of the kitchen or at least let them bring their plate back to the kitchen'. But they [home care assistants] feel like, 'But it only takes a second for us to do it' (Physiotherapist 3).

For patients, balancing the sometimes conflicting opinions of different professionals can be difficult. Besides challenges that occur daily, as illustrated in the quote above, having to deal with multiple conflicting messages can make patients lose sight of their treatment plan. Most professionals feel this applies especially to patients with low or deteriorating cognitive abilities. As the next quote illustrates, this may also lead to negative effects for professionals.

"Patients often say, 'The GP said so-and-so'. And then I find out it's not true and I'm like, huh? So there's lots of confusion because everyone has their own idea, [...] the caregivers and the client as well. And if it isn't coordinated properly you get situations where clients say, 'The GP told me I'll be getting physiotherapy twice a week'. Then I say, 'Well, it's not up to the GP to decide this, it happens in consultation with me'. So you notice that we [professionals] are being played off against each other, just because things aren't clear" (Physiotherapist 2). Different ideas about who is the central figure in the team can also cause challenges between professionals. This often has to do with patients' central focus on the GP, which can again impact the active role patients actually or are willing to play in their care. The 'Doctor knows best' attitude can cause challenges between patients and other professionals when the patient values the professional's opinion less than the GP's. Then, professionals other than GPs face the challenge of convincing the patient of the necessity of a specific treatment, as the next quote illustrates.

"I see that elderly patients are very focused on authority. If I say 'you're allowed to move around' and the patient tells me 'No, the doctor told me not to move'. I can jump high or low, it won't make any difference. The doctor has a higher position in the hierarchy" (Occupational therapist 2).

Informal caregivers as undesirable leaders of the team

Third, challenges can arise when informal caregivers attribute a central role to themselves while patients have different ideas on this. Some informal caregivers act independently without involving the patient. This could be because the patient is no longer capable of understanding their situation, leaving the informal caregiver in charge. However, some informal caregivers tend to act on what they believe the patient wants without verifying their thoughts with the patient. In these situations, informal caregivers could take the lead in conversations with professionals, while the patient would have liked to make his own decisions.

"For people who get lots of informal caregiving, I see their informal caregiver wants to set the care goals. Daughters, especially, bypass their parents. They just say, 'I'd like my mother to walk again', but they don't realize that their mother might not ever be able to walk again. Meanwhile, mother is sitting there, looking at me, like 'walking is not my first priority'" (Physiotherapist 3).

Also, informal caregivers can be overprotective of family members, which causes them to go against professional advice. Some children believe that their parents have a right to more intensive care either the professionals or the patients feel is desirable or required. This creates challenges for patients to express their own wishes and also challenges for professionals to deal with this kind of behaviour in informal caregivers.

"Some informal caregivers feel that their parent doesn't get enough care and is entitled to more. So they defend their parent's right to care. They ask you 'What is that ointment for?' When you explain, they say, 'But I read this and that on the Internet, so you're wrong'. So then you tell them, 'No, it's not wrong, it has the same effect'. They don't have a professional background, and that can cause lots of confusion between us". (District nurse 1).

Challenges can be even greater when patients receive support not from one informal caregiver, but a group of them. Often in the parent-child caregiving relationship, elderly patients receive care and support from all their children whose opinions may not always align.

DISCUSSION

In this study we openly explored the perspectives of patients, informal caregivers and primary care professionals on patient involvement in the decision-making process in interactions in primary care teams. Adding to the literature showing that patient involvement depends on the quality of the relationships between patients, informal caregivers and professionals (Bastiaens et al., 2007; Davis et al., 2007; Smith et al., 2009), our multi-perspective study reveals that misalignments in both views and expectations of the role division influence interactions and patient involvement accordingly. Patient involvement is a relational process, shaped in a context of reciprocal relationships between patients, informal caregivers and professionals (Thompson, 2007). Professionals do not often consider patients and informal caregivers to be part of the team (Dongen et al., 2017; LaDonna et al., 2016). However, viewing patients and informal caregivers as team members is important for delivering high quality care, as some patients and informal caregivers have vital experiential knowledge and can therefore play crucial roles in the care-provision process (Bagchus et al., 2015; Dongen et al., 2017; Pomey et al., 2015). Recognizing the roles of both patients and their informal caregivers in the team could help professionals understand and collaborate better with them and thus limit the likelihood of challenges occurring in their interactions.

Challenges within the team

This study found three challenges caused by different perspectives and expectations of patient involvement in the primary care team. The first challenge is that professionals tend to consider themselves the team leader and fall into a 'repair reflex', which may lead patients to feel misunderstood and less involved in the team than they would like. Research on self-management of patients finds a similar repair-reflex in home care nurses (Dwarswaard & van de Bovenkamp, 2015).

The second challenge is that patients need to balance the sometimes conflicting opinions of multiple professionals. Research of Doekhie and colleagues (2017) shows that primary care professionals have misaligned views on who is the most important person in the care for a patient. General practitioners often consider themselves the key figure and physiotherapists and occupational therapists, for example, as less important, while the latter two professionals

do find themselves important figures in the care process (Doekhie et al., 2017). Following this research, our study shows that the professional's idea of who the key figure in the team is and whose opinion should be leading could lead to challenges that impact patient involvement.

The third challenge concerns the role of informal caregivers in the team, and how they may have a different opinion than patients and professionals of the (desired) level of patient involvement in the team. This may prompt informal caregivers to take over the lead in the team (Gallant et al., 2007). The expectations of patients and professionals on a patient's responsibilities and abilities may be in alignment, but their actions would be hindered by a dominant informal caregiver who has opposing or deviating expectations of what the responsibility of their loved one should be.

Although aligning the expectations of patients, informal caregivers and professionals could be seen as a scenario worth pursuing, doing so could also mean that a patient would prefer to be less involved than others may think. This notion challenges the underlying assumptions of current health policies in various countries. In Thompson's taxonomy of patient involvement, the desired levels of patient involvement range from autonomous decisionmaking to non-involvement and the actual level is influenced by the relationship between patients and their caregivers as well as the patient's own capacity (e.g. cognitive ability) (Thompson, 2007). From a policy perspective, patient involvement is highly valued and should be pursued (Bovenkamp & Dwarswaard, 2017; Sheridan et al., 2015). Patients are encouraged to make autonomous decisions and non-involvement is considered undesirable. Paradoxically, however, this decision may also include patients' non-involvement in their care process, or put differently, a strong desire to place decision-making in the control of their informal caregivers and primary care professionals (Dwarswaard & van de Bovenkamp, 2015). The question then becomes whether active patient involvement should be imposed on those patients who want to remain passive. From our perspective, patient-centred care implies accepting that patients have distinct preferences in the level and type of involvement, which may change over time and also depend on their current ability (Bastiaens et al., 2007). Actual involvement of patients in the decision-making process is shaped on the micro-level in teams of patients, informal caregivers and professionals.

Limitations

Our study on patient involvement looked solely at chronically ill elderly patients and this should be considered when interpreting the results. However, other research shows that the level of patient involvement also differs in younger and not chronically ill patients and is also influenced by the quality of the relationships with care providers (Thompson, 2007). This suggests that our findings are still generalizable to other patient groups.

Patients and informal caregivers were selected on the basis of recommendations of the professionals and not at random. Because of this, we could have potentially excluded patients and informal caregivers who are less willing or able to speak openly, but who might have had interesting insights into the interactions of the team. However, our patient group differed in their extent of preferred and actual involvement and our informal caregiver group differed in their extent of stimulating or hindering patient involvement. As a result, we were able to examine several types of interactions and relationships between actors, which provided us with a broad insight into the sometimes conflicting perspectives and expectations of all the actors concerned with patient involvement in the team decision-making process.

The relatively low number of interviews per respondent group could be seen as a limitation. However, data saturation was reached. Also, the purpose of our study was to openly explore patient involvement in the primary care team, and so we tried to include as many different perspectives as possible to gain broad insight. For the same reason, we did not select primary care teams as a whole (i.e. one specific patient, his/her informal caregiver and all professionals involved in the care for that patient). Therefore, we cannot draw conclusions on patient involvement in specific teams of patients, informal caregivers and professionals. Future research could focus on exploring patient involved in specific teams.

Implications for practice

Our study shows that (mis)alignments in expectations of the roles and responsibilities of patients, informal caregivers and professionals influence patient involvement in the team. For patient involvement, it is important that professionals and informal caregivers acknowledge that the patient is indeed a part of the team. To achieve this recognition, a first step could be to clarify what the primary care team does and who its members are. Research shows that primary care professionals, viewing the roles of their professional colleagues, regard primary care teams as fluid entities with an inner and outer layer (e.g. Doekhie et al., 2017).

Our study indicates that patients may receive informal and professional care from various individuals. Therefore, the patient could be the single binding factor of the team and thus their primary care team should be conceptualised from the patient's perspective (LaDonna et al., 2016). To conceptualise primary care teams from a patient's perspective, the 'concentric circles of importance' could be used for the chronically ill elderly (Rogers et al., 2016). In this method, participants are asked to identify and describe the individuals involved in their care process and to value the importance of their role in various health related activities (Rogers et al., 2016). This method determines the different layers of the primary care team.

Moreover, previous research on teams has identified role clarification (i.e. understanding the mutual roles and responsibilities of team members) as an important factor that influences the effectiveness of a team (Lemieux-Charles & McGuire, 2006; Sargeant, Loney, & Murphy, 2008; Sheard & Kakabadse, 2002; Xyrichis & Lowton, 2008). To achieve role clarification, it is important to develop positive interpersonal relationships, based on the opportunity to build trust and respect (Xyrichis & Lowton, 2008). In line with other research we therefore suggest that patients could benefit from a meeting with their informal caregivers and involved professionals especially to discuss their preferences and abilities (Dongen et al., 2017; van Dongen et al., 2017). The presence of patients and informal caregivers at team meetings is shown to be appreciated by patients and professionals (Dongen et al., 2017). Role clarification is especially important for patients with multiple chronic conditions as a wide range of different primary care professionals could be involved in their care process, each having a different perspective on patient involvement (Doekhie et al., 2017; Dongen et al., 2017).

To compensate for hindering factors such as time constraints and geographical distance, role clarification regarding patient involvement could be integrated into existing regular inter-professional care-planning meetings. The use of modern virtual communication technologies, such as video-calling, would especially benefit geographically dispersed patients, informal caregivers and professionals so that these individuals could follow meetings without needing to be physically present (Ale Ebrahim, Ahmed, & Taha, 2009; Berry, 2011).

CONCLUSION

Patient involvement could be enhanced by considering the individual perspectives and expectations of patients, informal caregivers and primary care professionals. In the primary care setting, patient involvement is not up to the individual patient or the result of bidirectional relations between one patient and one informal caregiver or professional. Rather, it is shaped in the complex interactions between patients, informal caregiving and various primary care professionals whose perspectives of patient involvement may diverge greatly.

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CHAPTER 5

Trust in older persons: A quantitative analysis of alignment in triads of older persons, informal carers and home care nurses

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ABSTRACT

Self-management by elderly patients could be influenced by the level of trust found in triads of informal caregivers, formal care providers and care recipient, the elderly patient. Little research has been done on care professionals' trust in elderly patients. This study aims to explore the level of trust that informal caregivers and home care nurses have in elderly patients, the extent of alignment in triads and the relationship between trust in elderly patients and self-management. We conducted a cross-sectional survey study in the Netherlands, sampling 133 elderly patients, 64 informal caregivers and 72 nurses, which resulted in 39 triads. Alignment level was analysed through Intraclass Correlation Coefficient 1 scores and absolute and mean difference scores. Correlation analysis and one-way analysis of variance measured the relationship between trust and self-management. The results show that triads contain both alignment and misalignment. Misalignment occurs mostly when informal caregivers and nurses have little trust in the elderly patient while this person views their own behaviour towards their caregivers positively. Care professionals' trust levels relate significantly to their perception of the patient's ability to self-manage, but not to the patient's self-rated ability. This could be explained by care professionals and informal caregivers not communicating their intrinsic trust in the elderly patients to them. Trust building could be enhanced by organising discussions of mutual expectations of trust and both formal and informal care providers could benefit from compassionate assessment training, to learn how to openly express their trust in the elderly patient.

INTRODUCTION

Today, elderly patients are increasingly expected to manage their own health care and life (Hengelaar et al., 2016). This emphasis on self-management fits the policy trend in many western European countries to reduce institutionalised secondary care and encourage elderly patients to live at home for as long as possible in order to contain excessively growing healthcare costs (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Dahlberg, Demack, & Bambra, 2007; Kutzleben, Reuther, Dortmann, & Holle, 2016; Wittenberg, Kwekkeboom, Staaks, Verhoeff, & Boer, 2017). Self-management can be defined variously (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). This study defines self-management as "the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a (chronic) condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life" (Barlow et al., 2002). Put differently, self-management refers to a patient's attitudes, behaviours and skills to cope with the impact of their (chronic) condition on their daily life, for example by exercising more and making dietary changes, or symptom management such as self-monitoring glucose levels (Barlow et al., 2002; Lawn & Schoo, 2010).

Elderly patients do not manage their health in isolation from their social environment. Rather, successful self-management depends on a person's collaborative relationships with both informal and formal care providers (Dwarswaard, Bakker, Staa, & Boeije, 2016; van Hooft et al., 2015; Whitehead, Jacob, Towell, Abu-qamar, & Cole-Heath, 2018). A growing stream of literature focuses on triads of care recipient (elderly patient), informal and formal care providers and how the quality of their relationships influences self-management (Adams & Gardiner, 2005; Bovenkamp & Dwarswaard, 2017; Hengelaar et al., 2016; Lindahl, Lidén, & Lindblad, 2011; Wiechula et al., 2016). Self-management is, for example, conceptualised as "*mutual participation between patients and caregivers*" and "*the conjunction with family, community and health-care professionals*" (Richard & Shea, 2011). Lindahl and colleagues (2011) emphasise the importance of building friendships between triad members to ensure that the recipient's needs are met and to develop stable relationships in which all involved treat each other as equals.

Trust is a keystone in triads of elderly patients, informal caregivers and formal care professionals (Hall et al., 2002; LoCurto & Berg, 2016; Pelaccia et al., 2016; Thorne & Robinson, 1988; Wiechula et al., 2016). It is closely related to other important aspects of relationships such as satisfaction, communication and privacy (Hall, Dugan, Zheng, & Mishra, 2001). Elderly patients' trust in their care professional and informal caregiver can influence their involvement in decision-making (Brown et al., 2002; Kraetschmer, Sharpe, Urowitz, & Deber, 2004) and perceived self-management ability (Bonds et al., 2004; Gabay, 2015; Young, Len-Rios, Brown, Moreno, & Cox, 2017). Research shows that trust between elderly patients and their care providers is important for continuity of care, patient satisfaction and adherence to therapeutic recommendations (Brennan et al., 2013; Calnan & Rowe, 2008; Hall, Camacho, Dugan, & Balkrishnan, 2002; R. M. Kramer & Cook, 2004; LoCurto & Berg, 2016). Most studies define trust as "*an expectation that the other person will behave in a way that is beneficial, or at least not harmful, and allows for risks to be taken based on this expec<i>tation*" (Brennan et al., 2013; LoCurto & Berg, 2016; Mascarenhas et al., 2006; Moskowitz et al., 2011; Thom et al., 2011). In other words, to trust a person means expecting that their behaviour and word, promise or statement can be relied upon (Mascarenhas et al., 2006).

However, most studies look solely at the trust that the care recipient has in their care providers (Brennan et al., 2013; Thom et al., 2011; Wilk & Platt, 2016). Research on trust in the elderly patient-care professional relationships from both angles is scarce with most studies mentioning only briefly the care professionals' trust in (elderly) patients (Brennan et al., 2013; Kramer & Cook, 2004). A review by Wilk & Platt (2016) identified just two empirical articles on trust in elderly patients from the care professionals' perspective (Moskowitz et al., 2011; Thom et al., 2011).

As the concept of trust is embedded in the social context of triad interaction, the perspectives of care professionals and informal caregivers should be embraced (Brennan et al., 2013; Pelaccia et al., 2016; Thom et al., 2011; Thorne & Robinson, 1988; Wilk & Platt, 2016). The trend in elderly patient self-management has redefined a paternalistic elderly patientcare professional relationship to a patient-driven and patient-centred one (Brennan et al., 2013; Douglass & Calnan, 2016; Murray & McCrone, 2015; Pelaccia et al., 2016; Wilk & Platt, 2016). Thus care professionals need to trust that the elderly patient will behave in ways that benefit their own health, such as following a treatment plan or giving accurate information about their condition (Pelaccia et al., 2016; Thom et al., 2011; Thorne & Robinson, 1988). Trust should not be blindly assumed. Rather, the elderly patient has to show that they can 'earn' their care professionals' and informal caregivers' trust (Brennan et al., 2013). Meanwhile, research suggests that care professionals' trust could influence the behaviour of elderly patients (Calnan & Rowe, 2008; Kim, Kaplowitz, & Johnston, 2004; Thom et al., 2011). Rogers (2002) argues that by expressing trust, care providers positively contribute to the elderly patient's confidence in managing their health. One could argue that it is desirable to align the care professional's and informal caregiver's trust and the elderly patient's view of their own trustworthiness. Research by Pelaccia and colleagues (2016) shows that some care professionals label certain elderly patients as 'unreliable' and trust them less because, for example, they do not think they are being sincere or honest in answering questions, whereas the elderly patients feel that they are.

Aims of this study

This study is one of the first to shed light on trust in elderly patients from three perspectives: informal caregivers, home care nurses and elderly patients themselves. We explore the interpersonal character of trust in triads from multiple perspectives, showing how trust exists and occurs in relationships between specific persons, rather than focussing on merely a single perspective (Kenny, Kashy, Cook, & Simpson, 2006). We aim to gain deeper insight into the concept of trust in elderly patients within the triad, and how trust relates to selfmanagement ability. In doing so, we explore trust and its relationship to self-management from all three individual perspectives, and also on the level of alignment in trust between the three triad groups and how (mis)alignment relates to self-management.

METHODS

Design and participants

We conducted a cross-sectional survey study in the Netherlands. The questionnaire focused on *interpersonal* trust between the care recipient and their informal caregivers and nurses and excludes institutional or systemic trust (in collective entities or organisations) (Douglass & Calnan, 2016; Hall et al., 2002). The study population consisted of triads of elderly patients, their informal caregivers and the most-involved home care nurse. Nurses were selected as the care professional group, as elderly patients living at home often receive home care and thus interact often with these nurses (Lindahl et al., 2011). Trusting relationships are important in these care triads (Lindahl et al., 2011; Weman & Fagerberg, 2006; Wiechula et al., 2016).

All elderly patients received care from one large home care organisation active in many cities in the west and south of the Netherlands. Inclusion criteria were: aged 60 or older, and receiving home care at least two days per week for six months or longer. All nurses worked for the same home care organisation. Informal caregivers were defined as family members (partners or children), close friends or neighbours who provide non-professional, voluntary care (Janse, Huijsman, Looman, & Fabbricotti, 2018).

Elderly patients gave written informed consent to participate in the study. For the informal caregivers and nurses, informed consent was assumed by their completion of the questionnaire. All questionnaires were filled in anonymously. The three participants belonging to a triad were given a unique identification number to distinguish triads. The names linked to these numbers were saved in an encrypted file made was made available to the main researcher (KD) only.

Data collection

Data were collected between July 2016 and December 2017. The home care organisation randomly selected 2000 elderly patients in their database, based on two criteria: (a) persons aged 60 years or older and (b) receiving care at least two days per week (figure 5.1). An informative letter and consent form were sent to the selected persons. The home care organisation forward contact details to the research team only when the elderly patient had given

informed written consent (n=343). At no point did the researchers have access to contact details without the elderly patients' written consent. Reasons for not giving consent and any background information on non-responders could not be collected to ensure their privacy.

KD and two other researchers visited the elderly patients at home, collecting data through structured interviews, audiotaped with informed consent. The interviews were recorded as most participants gave elaborated on their personal situation. The tapes were used only in the data analysis phase to gain a better understanding of the given scores.

The researchers asked if and from whom the elderly patient received informal care (n=89) and handed over a questionnaire for the informal caregiver, including an informative letter and return envelope. The questionnaires for nurses were distributed through their team leaders. The nurse's informative letter stated the name of the elderly patient concerned in the questionnaire and a return envelope. Seventeen nurses received separate questionnaires for two elderly patients; one nurse received questionnaires for three patients.





Instruments

Different questions were designed for each respondent group, focussing on two aspects: (a) care professionals' and informal caregivers' trust in elderly patients and the elderly patient's view of their own behaviour and (b) the self-management ability of the elderly patient (figure 5.2).

Examples of descriptive variables in the elderly patients' questionnaire are: age, gender, marital status, educational status and health status. Health status was assessed by the validated five-dimensional, three level EuroQol instrument (EQ-5D-3L) and the EuroQol visual analogue scale (EQ VAS) (Szende, Janssen, & Cabases, 2014). The EQ-5D-3L dimen-

sions are: mobility, self-care, usual activities, pain/discomfort and anxiety (Szende et al., 2014). The EQ VAS was used to rate elderly patients' self-rated health on a vertical analogue scale ranging from zero (worst imaginable health state) to 100 (best imaginable health state) (Szende et al., 2014).

Descriptive variables in the informal caregivers' questionnaire were: age, gender, marital status, educational status, living status, relationship to person and type of care/support for the person. Descriptive variables in the nurses' questionnaire were: age, gender, educational status, number of years nursing experience and number of years involved in caring for this elderly patient.

The 12-item Physician Trust in the Person scale (Thom et al., 2011) measured the trust level in elderly patients of the informal caregiver and nurse as well as the patient's assessment of their own behaviour. The first to measure trust *in* a patient by a formal care provider (Brennan et al., 2013; Thom et al., 2011), this scale is designed to gain insight into an under-researched topic (i.e. trust in patients) and a better understanding of how trust in patients and the processes in a care provider-patient relationship could lead to improvements in quality of care and care provider and patient satisfaction. Each item reflects on a specific type of behaviour of the elderly patient towards the informal caregiver and nurse, in terms of the patient's role in the relationship (e.g. whether patients understand what they are told) and the patient's respect for personal boundaries (e.g. whether patients make unreasonable demands) (Thom et al., 2011).



Figure 5.2. Trust and self-management in the questionnaires

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Three items with regard to informal care were excluded from the informal caregivers' and the elderly patients' questionnaires: provide information on used medicines, manipulate the office visit for secondary gain, and keeps their appointments. The first item was excluded based on insights from the research team's prior studies on the elderly patient-informal caregiver relationship, which indicate that patients rarely discuss their medicine list with their informal caregiver. The other two items were excluded as informal caregivers provide care at home, not in an office, and care delivery is often ad-hoc and not primarily arranged to suit the informal caregiver's schedule. The latter two were also excluded from the home care nurses' questionnaire, as home care is provided at a patient's home and not in an office and within specific time frames and not by scheduled appointments that patients have to keep like in hospitals.

The informal caregiver and nurse were asked how confident they were in the patient's behaviour towards them, using a five-point scale ranging from 1 (not at all confident) to 5 (completely confident). An item in the informal caregiver questionnaire was: "How confident are you that this patient will tell you about a major change in their condition?" An item in the nurse questionnaire was: "How confident are you that this patient will respect your personal boundaries?" Cronbach's alpha for the informal carer-adapted scale was 0.91 and for the nurse-adapted scale 0.91.

For the elderly patient questionnaire, the Physician Trust in Patient scale items were reformulated to statements, so that patients would assess behaviour towards either the informal caregiver or nurse [hereafter referred to as: patient's behaviour]. Each question was duplicated so that elderly patients could rate their answers for both informal caregiver and nurse on a five-point scale ranging from 1 (completely disagree) to 5 (completely agree). Questions included "I tell my informal caregiver if there are major changes in my condition" and "I respect the personal boundaries of the home care nurse." Cronbach's alpha for the elderly patient-adapted scale was 0.71 for informal caregivers and 0.64 for the nurse.

Self-management was measured using one of the nine scales of the Health Literacy Questionnaire instrument (HLQ): the 'ability to actively manage my health' scale (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). The HLQ addresses health literacy as a multidimensional concept and contains nine validated scales that measure distinct dimensions of health literacy and can be used independently to measure a distinct dimension of health literacy (Osborne et al., 2013). The scale this study used focuses on the extent to which patients take responsibility for their own health (Osborne et al., 2013).

This study used the original 'ability to actively manage my health' scale for the elderly patients, whereas the rephrased items for the nurse and informal caregiver, using a four-point scale ranging from 1 ("strongly disagree") to 4 ("strongly agree") on all three questionnaires. One item in the elderly patient questionnaire was: "I plan what I need to do to be healthy" and in the nurses and informal caregivers' questionnaires: "This patient makes time to be healthy despite having other things in their life." Cronbach's alphas were 0.87 for the elderly

patient questionnaire, 0.92 for the informal caregiver questionnaire and 0.94 for the nurse questionnaire.

Data analysis

Data were analysed using IBM SPSS 23.0. Regarding the first aim, the level of alignment between perceptions of trust was calculated in two ways. Firstly, we calculated the Intraclass Correlation Coefficient 1 (ICC1) scores to determine the level of agreement between the care nurses' and informal caregivers' levels of trust in the elderly patient in relation to the elderly patient's view of their own trusting behaviour. The strength of agreement reflected by ICC1 was labelled in concordance with other research: ≤ 0.40 poor to fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 good agreement, and 0.81–1.00 excellent agreement (Landis & Koch, 1977; Poort et al., 2016). Secondly, for each triad we calculated difference scores of trust using the absolute scale scores on the Physician Trust in the Patient scale. Sum scores per respondent group were first calculated. For example, in the patient questionnaire, their behaviour towards the informal caregiver and the latter's level of trust were measured with nine items of the scale, thus the sum score was the total of all nine items. Next, the sum scores of two respondent groups were subtracted to calculate the difference scores. To calculate the empirical range of difference scores, the minimum and maximum sum scores per respondent group were first calculated. Given the use of a five-point scale, the minimum sum score for the elderly patients' view of their own behaviour towards the informal caregiver and the latter's level of trust sum score is nine (score of one times nine items) and their maximum sum score is 45 (score of five times nine items). Therefore, the minimum difference score is the situation in which the informal caregiver would have a minimum score and the elderly patient would have the maximum score, leading to a score of -36 (9 minus 45) and the maximum score is the reversed situation, leading to a score of +36 (45 minus 9). The difference scores and empirical ranges were calculated in a similar manner for the other relationships in the triads.

Pearson correlation analysis was used to assess the relationship between the difference scores. Next, each triad was categorised as an alignment or misalignment based on the mean difference score for each dyadic relationship in the triad (informal caregiver – elderly patient; nurse – elderly patient; nurse – informal caregiver).

One-way analysis of variance (ANOVA) was used to analyse the significant difference per dyadic relationship between the alignment categories in their mean difference trust scores.

Regarding the second aim, we used correlation analysis to analyse the relationship between both care providers' mean levels of trust and elderly patients' self-management ability. Oneway ANOVA analysis was used to analyse the relationship between the differences scores and patient's self-management ability.

RESULTS

Sample characteristics quantitative results

Of the 133 elderly patients, 64 informal caregivers and 72 home care nurses who filled in the questionnaire, the final sample consisted of 39 triads (figure 5.1).

Table 5.1 provides the descriptives of the sample. The average age of the elderly patients was 80.4 years, 41% was male and the majority was Dutch (94.9%). Around half of the elderly patients were widows or widowers (53.8%), lived alone (59%) and 16 respondents (41.03%) had a co-resident informal caregiver. Most patients suffered from Parkinson's disease (69.20%) and/or had a visual disability (51.30%). The percentages of male older patients and patients living alone is comparable with the Dutch older population (Statistics Netherlands (CBS), 2017; Statistics Netherlands (CBS), 2018). However, the sample did not represent the ethnic diversity of the Dutch older population, for example the large group of Turkish and Surinamese persons (Statistics Netherlands (CBS), 2018). The EQ-5D-3L utility score and the EQ5D VAS score were average (0.50 and 55.64 respectively). One sample test showed that that both scores are significantly lower than Dutch population norms (t = -7.77, p < 0.05 and t = -13.28, p < 0.05 respectively) (Szende et al., 2014).

	Patient	Patients		Informal caregivers		Home care nurses	
	N	%	N	%	N	%	
Age, mean (SD)	80.39 (7.98)		62.61 (15.54)		44.60 (11.43)		
Sex							
Male	16	41.00	12	31.60	1	2.60	
Marital status ^a							
Married	13	33.30	25	65.80			
Unmarried	0	0	6	15.80			
Divorced	3	7.70	2	5.30			
Widow/widower	21	53.80	3	7.70			
Registered partnership	2	5.10	2	5.30			
Educational status ^{a,b}							
Less than secondary school	8	20.50	9	23.70	0	0	
Secondary school / technical school	29	74.40	24	63.20	35	92.10	
College or above	2	5.10	5	13.20	3	7.90	
Living status ^a							
Alone	23	59.00	9	23.70			
With partner	15	38.50	22	57.90			
With partner and children	0	0	5	13.20			
With children	1	2.60	1	2.60			
With parent			1	2.60			

Table 5.1. Descriptives of triads (n=39)

	Patients		Informal		Home		
				caregivers		rses	
	N	%	Ν	%	Ν	%	
Ethnic background							
Dutch	37	94.90	37	94.90			
British	1	2.60					
Indonesian	1	2.60					
Aruban			1	2.60			
Canadian			1	2.60			
Total number of co-resident informal carer	16	41.03					
of which partner	15	93.75					
of which son/daughter (in law)	1	6.25					
EQ-5D-3L dimensions							
Mobility							
No problems	6	15.40					
Some problems	32	82.10					
Extreme problems	1	2.60					
Self-care							
No problems	19	48.70					
Some problems	12	30.80					
Extreme problems	8	20.50					
Usual activities							
No problems	10	25.60					
Some problems	18	46.20					
Extreme problems	11	28.20					
Pain/discomfort							
No problems	9	23.10					
Some problems	19	48.70					
Extreme problems	11	28.20					
Anxiety/depression							
No problems	27	69.20					
Some problems	10	25.60					
Extreme problems	2	5.1					
EQ-5D utility scores mean (SD)							
EQ-5D-3L utility score	EQ-5D-3L utility score 0.50 (0.29)						
EQ5D-VAS	EQ5D-VAS 55.64 (13.33)						
Chronic condition in the past 12 months (multiple	options possi	ble)					
Diabetes	12	30.80					
Damage due to a stroke	8	20.50					
Heart failure	12	30.80					
Cancer	6	15.40					

Table 5.1. Descriptives of triads (n=39) (continued)

Table 5.1. Descriptives of triads (n=39) (continued)

	Patients		Infor	Informal		ne
			caregi	vers	care nu	irses
	Ν	%	N	%	Ν	%
Asthma, COPD, bronchitis	17	43.60				
Arthroses	27	69.20				
Osteoporosis	11	28.20				
Parkinson's disease	1	2.60				
Problems with stability	20	51.30				
Hearing disability	17	43.60				
Visual disability	11	28.20				
Depression	8	20.50				
Average days per week home care, mean (SD)	4.58 (2.66	5)				
Average number of nurses per week, mean (SD)	5.38 (3.11	.)				
Average time (in minutes) per nurse visit, mean (SD)	19.31 (13.0)3)				
Relationship to elderly patient ^c						
Partner			14	37.81		
Son/daughter (in law)			18	48.60		
Grandson/granddaughter (in law)			1	2.70		
Nephew/niece/cousin			1	2.70		
Friend			2	5.40		
Neighbour			1	2.70		
Type of informal care (multiple options possible)						
Bathing and getting dressed			4	10.50		
Meal preparation			16	42.10		
Daily care			9	23.70		
Medication provision			8	21.10		
Housework			24	63.20		
Grocery shopping			32	84.20		
Administrative support			18	47.40		
Transport to doctor's office			26	68.40		
Number of years active as home care nurse $^{\rm b}$						
Under 10					19	50
Between 10 and 25					17	44.70
More than 25					2	5.30
Number of years involved in caring for patient ${}^{\rm b}$						
Under one					9	23.70
Between one and three					24	63.20
More than three					5	13.20

Note: SD = standard deviation

^a N = 38 due to missing data for one informal caregiver

^b N = 38 due to missing data for one nurse

 $^{\rm c}$ N = 37 due to missing data for two home care nurses

The average age of the informal caregivers was 62.6 year, 31.6% was male and the large majority was Dutch (94.9%). Informal caregivers were mostly married (65.8%) and about half were a son or daughter (in law) of the elderly patient (48.6%). Informal caregivers provided household support (63.2%), grocery shopping (84.2%) and transport to the doctor's office (68.4%). Compared to the Dutch population the informal caregiver sample is largely representative as 56% is female and 42% provides care for their parent (in law) (Klerk, Boer, Plaisier, & Schyns, 2016). The range of activities is comparable to the Dutch population, though the percentage of household support and transportation is slightly lower in the Dutch population (45% and 53% respectively) (Klerk et al., 2016).

Only one nurse was male (2.6%) and most nurses had looked after the patient for between one and three years (63.2%). The large group of female nurses is representative for all nurses in the participating home care organization.

Trust mean scores

On a scale of 1–5, Kolmogorov-Smirnov Test of Normality showed a normal distribution of the informal caregivers' and nurses' trust scores as well as the elderly patient's score with regard to the nurse (figure 5.3). For the elderly patient's score regarding the informal caregiver, the significance level was 0.05, suggesting a relatively normal distribution (figure 5.3). The mean informal caregiver's level of trust was 3.98 (SD=0.75) and the mean nurse's level of trust in the elderly patient was 4.01 (SD=0.61). The elderly patient's mean score on their behaviour, meaning the mean scores on the reformulated Physician Trust in the Patient scale [hereafter referred to as: patients view of their own behaviour] towards the informal caregiver was 4.56 (SD=0.41) and towards the 4.49 (SD=0.47) (table 5.2).



Trust variables1. Informal caregiver's trust in elderly patient 4 383.980.75.222. Home care nurse's trust in elderly patient394.010.613. Elderly patient's view on behaviour towards informal caregiver b 374.560.414. Elderly patient's view on behaviour towards home care nurse b 374.490.47Difference scores on trustS. Trust informal caregiver a 38-4.1810.19S. Trust informal caregiver a 38-4.1810.19S. Trust informal caregiver a 38-4.1810.19S. Trust informal caregiver a 39-1.9711.62Outcome care nurse – elderly patient3. Trust home care nurse – elderly patient394.268.04Outcome variable self-managementOutcome variable self-management	0.75 0.61 0.41 0.47 0.47	.22	.03	.16 00 .49*					
1. Informal caregiver's trust in elderly patient a 383.980.75.222. Home care nurse's trust in elderly patient394.010.613. Elderly patient's view on behaviour towards informal caregiver b 374.560.414. Elderly patient's view on behaviour towards home care nurse b 374.490.47Difference scores on trustA.560.41O.47Difference scores on trust5. Trust informal caregiver a 38-4.1810.19O. Trust home care nurse b 37-4.1810.19O.4738-4.1810.19Trust informal caregiver a 38-4.1810.19Trust home care nurse a 38-4.268.04Outcome variable self-management	0.75 0.61 0.41 0.47 0.47		.03	.16 00 .49*					
2. Home care nurse's trust in elderly patient 39 4.01 0.61 3. Elderly patient's view on behaviour towards informal caregiver ^b 37 4.56 0.41 4. Elderly patient's view on behaviour towards home care nurse ^b 37 4.49 0.47 4. Elderly patient's view on behaviour towards home care nurse ^b 37 4.49 0.47 Difference scores on trust 38 -4.18 10.19 6. Trust informal caregiver ^a 38 -1.97 11.62 7. Trust home care nurse – informal caregiver ^a 38 4.26 8.04 7. Trust home care nurse – informal caregiver ^a 38 4.26 8.04	0.61 0.41 0.47 10.19		03	00 .49*			.18	.47*	.47*
3: Elderly patient's view on behaviour towards informal caregiver ^b 37 4.56 0.41 4: Elderly patient's view on behaviour towards home care nurse ^b 37 4.49 0.47 Difference scores on trust 5 4.49 0.47 Difference scores on trust 5: Trust informal caregiver ^a 38 -4.18 10.19 6: Trust home care nurse - elderly patient 39 -1.97 11.62 7: Trust home care nurse - informal caregiver ^a 38 4.26 8.04	0.41 0.47 10.19			.49*			99	.20	.40**
4: Elderly patient's view on behaviour towards home care nurse ^b 37 4.49 0.47 Difference scores on trust 3 4.18 10.19 5: Trust informal caregiver-elderly patient 38 -4.18 10.19 6: Trust home care nurse - elderly patient 39 -1.97 11.62 7: Trust home care nurse - informal caregiver ^a 38 4.26 8.04 Outcome variable self-management 3 4.26 8.04	0.47 10.19						.51*	.28	.21
Difference scores on trust 38 -4.18 10.19 5. Trust informal caregiver- elderly patient ^a 38 -4.18 10.19 6. Trust home care nurse - elderly patient 7. Trust home care nurse - informal caregiver ^a 38 4.26 8.04 Outcome variable self-management 38 4.26 8.04	10.19						.37**	.10	.13
5. Trust informal caregiver- dderly patient a 38 -4.18 10.19 6. Trust home care nurse - elderly patient 39 -1.97 11.62 7. Trust home care nurse - informal caregiver a 38 4.26 8.04 Outcome variable self-management	10.19								
6. Trust home care nurse - elderly patient 39 -1.97 11.62 7. Trust home care nurse - informal caregiver ^a 38 4.26 8.04 Outcome variable self-management					.012	50*	00	.24	.20
7. Trust home care nurse - informal caregiver ^a 38 4.26 8.04 Outcome variable self-management	11.62					.29	20	031	.12
Outcome variable self-management	8.04						23	26	08
8. Elderly patient's self-rated self-management ability 39 2.71 0.51	0.51							.40**	.33**
9. Informal caregiver's perspective on self-management ^a 38 2.82 0.58	0.58								.38**
10. Home care nurse's perspective on self-management 38 3.00 0.44	0.44								

(within the empirical ranges), based on the sum scores on the trust scale. 1 n=38 due to missing data for one informal caregiver; 1 n=37 due to missing data for two elderly patients. In both cases, respondents did not fill in the whole scale.* Correlation is significant at 0.01 level (two-tailed) ** Correlation is significant at 0.05 level (two-tailed)

CHAPTER 5

On a scale of 1–4, the Kolmogorov-Smirnov test showed that self-management scores were not statistically normally distributed, though the histograms suggest a relatively normal distribution (figure 5.4). The elderly patient's self-rated self-management mean score was 2.71 (SD=0.51), the informal caregiver's perspective on the patient's self-management was 2.82 (SD=0.58) and the nurse's perspective was 3.00 (SD=0.44) (table 5.2).



Figure 5.4. Histogram distribution self-management scores from all three respondent groups

Level of alignment between informal caregivers, nurses and elderly patients

ICC1 – level of agreement

The ICC1 level (figure 5.5) for the informal caregiver's trust in the patient in relation to the patient's view of their own behaviour was 0.25 with a 95% confidence interval from -0.14 to 0.52. This indicates a non-significant, fairly low level of agreement between informal caregivers and elderly patients. The ICC1 score for the nurse's trust in the patient in relation to the patient's view of their own behaviour was 0.08 with a 95% confidence interval from -.25 to 0.36. This indicates a non-significant, very low level of agreement between nurses and elderly patients. The ICC1 score for the informal caregiver's trust in relation to the nurse's trust was 0.36 with a confidence interval ranging from -0.25 to 0.67, indicating a non-significant, fairly low level of agreement.





Each arrow represents the relationship between two respondent groups (e.g. older persons and nurses). For each relationship, the first number shows the Intraclass Correlation Coefficient 1 score (ICC1) and the corresponding confidence interval (CI). The second number shows the mean difference score (DS) and corresponding standard deviation (SD).

Difference scores on trust in patients

Difference scores for the level of trust in elderly patients were calculated for each triad using the absolute value of the difference between the informal caregiver's and nurse's trust in the patient and the patient's view of their own behaviour towards both kinds of care provider (figure 5.5 and table 5.2). Differences scores for the informal caregiver and elderly patient were calculated with the absolute scores of the informal caregiver minus the patients' absolute scores (empirical range between -36 and +36). Differences scores for the nurse and the elderly patient were calculated with the absolute scores of the nurse minus the absolute scores of the patient (empirical range between -40 and +40). Difference scores between the nurse and informal caregiver were calculated with the absolute scores of the nurse minus the informal caregiver's scores (empirical range between -35 and +41).

Between the informal caregiver and the elderly patient and between the nurse and the elderly patient, negative mean difference scores were found (table 5.2) (-4.18 and -1.97 respectively). This means that the level of trust of both care providers in the patient is lower than the patient's view of their own behaviour towards both care providers. Between the nurse and informal caregiver, the mean difference score was 4.26, implying that on average the nurse had more trust in the elderly patient than the informal caregiver.
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	Informal	caregiver – patie	ent dyad ^a	Home G	ıre nurse – patie	ent dyad	Home care nu	ırse – informal e	aregiver ^a
	$\mathbf{Ic} < \mathbf{p}^{\mathrm{b}}$	Alignment	Ic > p	Hcn [°] < p	Alignment	Hcn > p	Hcn < ic	Alignment	Hcn > ic
Z	18	18	7	23	9	10	Ś	14	19
Mean difference score (SD)	-11.39 (4.67)	-0.06 (2.24)	23.50 (24.79)	-8.91 (4.80)	-0.17 (0.75)	12.90 (11.95)	-9.20 (3.35)	0.79 (2.89)	10.37 (5.04)
Min/Max	-23.00 / -5.00	-4.00 / 4.00	6.00 / 41.00	-20.00/ -3.00	-1.00 / 1.00	4.00 / 40.00	-13.00 / -5.00	-4.00 / 4.00	5.0 / 25.00
F-statistic (P-value)		45.47 (0.00*)			33.51 (0.00*)		U V	(1.21 (0.00*)	
Note: Categories were based on	1 the average differ	ence scores in e	ach dyadic relatic	onship.					

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triads

^a N = 38 for the informal caregiver-patient dyad and home care nurse-informal caregiver dyad because data are missing for one informal caregiver.

^b Icp = Informal caregiver; p = elderly patient

* *F*-statistic significant at 0.01 level ^c Hcn = home care nurse

Correlation analysis (table 5.2) revealed a significant negative correlation between the difference score of the informal caregiver and elderly patient and the difference score between the nurse and informal caregiver (r. = -0.50; p < 0.01). This means that the level of alignment between the informal caregiver and the elderly patient negatively influences the level of alignment between the nurse and informal caregiver, and vice versa.

The difference scores for each triad were grouped in three categories to gain more insight into the level of alignment and misalignment in triads (table 5.3). Categories were based on the mean difference score of each dyadic relationship in the triad. One-way ANOVA showed significant differences per dyadic relationship between the three alignment categories in their mean difference score. Between the informal caregiver and elderly patient, misalignment was found in 18 triads in which the informal caregiver had a lower level of trust than the patient's view of their own behaviour (mean= -11.39, SD=4.67), but another 18 triads showed alignment (mean = -0.06, SD=2.24). Between the nurse and elderly patient, six triads had an alignment and 23 triads showed misalignment with the nurse having a lower level of trust in the patient than the patient's view of their own behaviour (mean = -8.91, SD=4.80). Between the nurse and informal caregiver, 14 triads had alignment and 19 triads had misalignment in which the nurse's level of trust in the patient was higher than the informal caregiver's level of trust (mean= 10.37, SD=5.04).

The descriptive characteristics of the triads per (mis)alignment category are provided in table 5.4. In the relationship between informal caregivers and elderly patients, the misalignment category in which informal caregivers had a higher level of trust than the elderly patient's view of their own behaviour, none of the informal caregivers was a partner or coresident. In the relationship between the nurse and elderly patient, the alignment category is characterized by patients with higher EQ-5D-3L scores (0.69) and a lower average time per home care visit (9.67 minutes) than the two misalignment categories (EQ-5D-3L scores 0.48 and 0.45; average time per home care visit (20.44 and 22.50 minutes respectively). In the relationship between nurses and informal caregivers, the patient's EQ-5D-3L score was substantially lower in the alignment category (0.38) than in the other two categories (0.59 and 0.60 respectively.

Self-management ability of the patient

Correlation analysis was performed to analyse the relationship between the trust variables and self-management (table 5.2). Significant relationships were found between the elderly patient's view of their own behaviour towards the informal caregiver and the nurse and the patient's self-rated self-management ability (r. = 0.51, p <0.01; r. =0.37, p < 0.05 respectively). This means that when elderly patients had a positive view of their own behaviour towards either care provider, they also had more confidence in their self-management ability and vice versa.

4		>							
1. Informal care provider – elderly patient	dyad								
	Informal care	giver < elderly p	atient (n=18)	Alignment	informal caregiv patient (n=18)	er – elderly	Informal care	:giver > elderly p	atient (n=2)
	Р	Icp ^a	$\operatorname{Hcn}^{\mathrm{b}}$	Ρ	lcp	Hcn	Ρ	Icp	Hcn
Age, mean (SD)	78.44 (8.79)	61.78 (13.94)	42.40 (11.69)	83.28 (6.31)	64.12 (18.34)	46.59 (11.31)	78.50 (4.95)	58.00 (4.24)	37.00 (4.24)
Gender male, N (%)	8 (44.40)	4 (22.20)	0	7 (38.9)	7 (38.90)	1 (5.6)	1 (50.00)	1 (50.00)	0
Educational background, $\mathrm{N}~(\%)$									
Less than secondary school	6 (33.30)	4 (22.20)		1 (5.60)	4 (22.2)		1 (50.00)	1(50.00)	
Secondary school / technical school	10 (55.60)	12 (66.70)	16 (94.10)	17 (94.40)	11 (61.10)	16 (88.90)	1 (50.00)	1 (50.00)	2 (100)
College or above	2 (11.10)	2 (11.10)	1 (5.3)	0	3 (16.70)	2 (11.10)	0	0	
EQ-5D-3L utility score, mean (SD)	0.54 (0.33)			0.48(0.26)			0.54(0.03)		
EQ-5D VAS score, mean (SD)	55.00 (11.88)			58.89 (14.20)			40.00(0.00)		
Co-resident informal care provider (yes), N (%)	7 (38.90)			8 (44.44)			0		
Relationship to older person, N (%)									
Partner		7 (41.20)			7 (38.90)				
Son/daughter (in law)		8 (47.10)			9 (50.00)			1(50.0)	
Grandson/granddaughter (in law)					1 (5.60)				
Nephew/niece/cousin		1 (5.90)			0				
Friend		1 (5.90)			0			1(50.0)	
Neighbour					1 (5.60)				
Average days per week home care, mean (SD)	5.03 (2.53)			4.10 (2.76)			3,15 (1.56)		
Average number of home care nurses per week, mean (SD)	6.37 (3.52)			4.36 (1.96)			3.00(0)		
Average time (in minutes) per home care nurse visit, mean (SD)	19.93 (12.03)			16.61 (12.34)			5.00 (7.07)		

Table 5.4. Descriptive characteristics of the triads per (mis)alignment category of table 5.3

2. Home care nurse – elderly patient dyad	<								
	Home care n	urse < elderly p	atient (n=23)	Alignment	home care nurs patient (n=6)	ie – elderly	Home care nu	arse > elderly p	atient (n=10)
	Ъ	Icp ^c	Hcn	Ъ	Icp	Hcn	Ъ	Icp	Hcn
Age, mean (SD)	79.78 (8.01)	62.33 (14.27)	42.70 (10.78)	50.17 (13.15)	50.20 (23.92)	81.50 (4.04)	81.10 (10.04)	69.40 (9.78)	45.11 (12.39)
Gender male, N (%)	6 (26.10)	8 (36.40)	1 (4.30)	3 (50.00)	1 (16.70)	0	7 (70.00)	3 (30.00)	0
Educational background, $\mathrm{N}~(\%)$									
Less than secondary school	6 (26.10)	7 (31.80)	19 (86.40)	0	0	0	2 (20.00)	2 (20.00)	0
Secondary school / technical school	16 (69.60)	13 (59.10)	3 (13.60)	6 (100)	6(100)	6 (100)	7 (70.00)	5 (50.00)	10 (100)
College or above	1 (4.30)	2 (9.10)	0	0	0	0	1(10.00)	3 (30.00)	0
EQ-5D-3L utility score, mean (SD)	0.48 (0.31)			$0.69\ (0.20)$			0.45 (0.27)		
EQ-5D VAS score, mean (SD)	53.70 (12.63)			63.33 (15.38)			55.50 (13.43)		
Co-resident informal care provider (yes), N (%)	6 (26.09)			2 (33.33)				7 (70.00)	
Relationship to elderly patient, $N~(\%)$									
Partner		6 (26.10)			2 (33.33)			6~(60.00)	
Son/daughter (in law)		12 (52.20)			3 (50.00)			3 (30.00)	
Grandson/ granddaughter (in law)					1 (16.78)				
Nephew/niece/cousin		1 (4.30)							
Friend		2 (8.70)							
Neighbour								1(10.00)	
Average days per week home care, mean (SD)	5.28 (2.25)			4.17 (3.25)			3.40 (2.95)		
Average number of home care nurses per week, mean (SD)	5.59 (3.39)			5.00 (2.00)			5.00 (3.16)		
Average time (in minutes) per home care nurse visit, mean (SD)	20.44 (10.33)			9.67 (7.12)			22.50 (18.75)		

3. Home care nurse – informal caregiver dy	yad								
	Home care	: nurse < inforn	nal caregiver	Alignment	home care nurs	e – informal	Home care	nurse > informa	ıl caregiver
		(n=5)			caregiver (n=14			(n=19)	
	Р	Icp	Hcn	Ρ	Icp	Hcn	Ρ	Icp ^d	Hcn ^d
Age, mean (SD)	81.40 (4.93)	54.60 (5.68)	47.40 (10.33)	82.14 (6.76)	65.92 (20.21)	41.00 (10.24)	79.53 (9.09)	62.44 (13.20)	46.07 (12.50)
Gender male, N (%)	3 (60.00)	1 (20.00)	0	2 (14.30)	7 (50.00)	1 (7.10)	11 (57.90)	4 (21.10)	0
Educational background, N (%)									
Less than secondary school	1 (20.00)	2 (40.00)	0	2 (14.30)	3 (21.43)	0	4 (21.10)	0	0
Secondary school / technical school	4 (80.00)	3 (60.00)	5 (100)	12 (85.70)	10 (71.43)	12 (85.70)	11 (57.90)	17 (94.40)	17 (94.40))
College or above	0	0	0	0	1 (7,14)	2 (14.30)		1 (5.60)	1 (5.60
EQ-5D-3L utility score, mean (SD)	$0.59\ (0.20)$			0.38(0.33)			0.60 (0.25)		
EQ-5D VAS score, mean (SD)	54.00 (16.73)			55.36 (12.16)			57.11 (13.78)		
Co-resident informal care provider (yes), N (%)	0			6 (42.86)			9 (47.37)		
Relationship to older person, N (%)									
Partner		0			6 (46.86)			8 (42.11)	
Son/daughter (in law)		4(80.00)			6 (46.86)			8 (42.11)	
Grandson/ granddaughter (in law)					1 (7.14)				
Nephew/niece/cousin								1 (5.26)	
Friend		1 (20.00)						1 (5.26)	
Neighbour								1 (5.26)	
Average days per week home care, mean (SD)	3.50 (2.11)			5.21 (2.45)			4.42 (2.79)		
Average number of home care nurses per week, mean (SD)	4.25 (1.89)			5.00 (2.35)			6.13 (3.85)		
Average time (in minutes) per home care nurse visit, mean (SD)	10.00 (6.12)			20.71 (11.07)			20.16 (15.13)		
^a N= 17 for the informal caregivers' relation ^b N = 17 for the home care nurses' educatio ^c N = 22 for the informal caregivers' educat	aship to patient and level due to tional level due t	due to missing missing data o o one missing	data on this van n this variable f data and n= 21	iable for one in or one nurse for the relation	nformal caregiv ship to elderly	er patient due to 1	missing data fo	r two informal c	aregivers
$^{\circ}$ N = 18 for the informal caregivers and nu	urses' educationa	al level due to r	nissing data for	one in both gr	sdno				

Table 5.4. Descriptive characteristics of the triads per (mis)alignment category of table 5.3 (continued)

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Outcome variable: self-manageme	ent	Informal	caregiver-pati	ient dyad	Home c	are nurse-patie	ent dyad	Home care	e nurse-informa	al caregiver
2			•			×			<u>dyad</u>	>
		$Ic^a < p$	Alignment	Ic > p	$Hcn^b < p$	Alignment	Hcn > p	Hcn < ic	Alignment	Hcn > ic
	Z	18	18	2	23	6	10	5	14	19
	Mean (SD)	2.78 (0.38)	2.63 (0.66)	2.80 (0.28)	2.83 (0.32)	2.63 (0.37)	2.48 (0.83)	2.88 (0.23)	2.76 (0.38)	2.63 (0.65)
Elderly patients self- rating	<i>F</i> -statistic		0.37			1.83			0.53	
	<i>P</i> -value		0.70			0.18			0.59	
	z	18	18	2	22	6	10	5	14	19
···· · · · · · · · · · · · · · · · · ·	Mean (SD)	2.66 (0.49)	2.96 (0.66)	$3.00\ (0.00)$	2.79 (0.47)	3.00 (0.74)	2.76 (0.72)	2.80 (0.35)	3.17 (0.38)	2.56 (0.62)
uniormal caregivers perspective	<i>F</i> -statistic		1.35			0.36			5.70	
	<i>P</i> -value		0.27			0.70			0.01^{*}	
	Z	17	18	2	22	6	10	5	14	18
	Mean (SD)	2.88 (0.37)	3.13 (0.50)	2.70 (0.14)	2.96 (0.41)	3.10 (0.47)	3.02 (0.54)	2.92 (0.23)	3.09 (0.49)	2.94 (0.46)
riome care nuises perspective	<i>F</i> -statistic		1.92			0.23			0.46	
	<i>P</i> -value		0.16			0.80			0.64	

^b Hcn = home care nurse

* *F*-statistic significant at 0.01 level

Significant relationships were found between the informal caregiver's level of trust and their perception of the patient's self-management ability (r. =0.47, p <0.01) and with the perception of the nurse of the patient's self-management ability (r. 0.47, p <0.01). For the nurse's level of trust a significant correlation was found with their perception of the patient's self-management ability (r. = 0.40, p <0.05).

Difference scores and self-management of the patient

No significant relationships were found between the absolute differences scores and the patient's self-management ability in all three perspectives (table 5.2). Regarding the alignment categories, one-way ANOVA (table 5.5) showed no significance in the mean self-management scores of all three perspectives, with the exception of a significantly higher self-management score in the informal caregiver's perspective in alignment between the nurse and informal caregiver (F = 5.70, p < 0.01).

DISCUSSION

This study shows that in triads of elderly patients, informal caregivers and home care nurses, perceptions can both align and misalign regarding the care providers' level of trust in the elderly patient and the patient's view of their own behaviour. Notably, most triads had misalignments, with informal caregivers or nurses having a lower level of trust in the patient while the elderly patients viewed their own behaviour towards either care provider positively. Our study shows a negative relationship between the level of alignment between informal caregivers and elderly patients and the level of alignment between informal caregivers and nurses, implying that the level of alignment in one relationship in the triad could impact the level of alignment in another relationship in the triad. Therefore, our study supports the importance of taking triadic relationships and interactions as the starting point when analysing the interpersonal character of trust instead of examining individuals in isolation (Kenny et al., 2006). For example, Murray & McCrone (2015) show the importance of alignment in the expectations of informal caregivers or nurses and the behaviour of (elderly) patients, as alignment may enhance the quality and stability of mutual relationships. The misalignment between informal caregivers' and nurses' level of trust and the patients' view of their own behaviour could be explained by the fact that trust building depends on the levels of longevity and continuity of care and the extent to which positive interactions occur over time (Kramer & Cook, 2004), such as happens when a regular care professional frequently visits the person (Becker & Roblin, 2008; Bova, Fennie, Watrous, Dieckhaus, & Williams, 2006; Cunningham, Sohler, Korin, Gao, & Anastos, 2007). Research by Lindahl and colleagues (2011) indicates that facilitating contact between individuals is important in creating

a sense of familiarity that could lead to the establishment of a trusting relationship. In our study, the nurses spent about 20 minutes with each elderly patient. This limitation, as well as the restricted opportunity for positive interaction between the nurse and elderly patient and possibly also between nurse and informal caregiver (who does not live with the patient) could reduce the time available to build mutual trusting relationships in these triads.

Moreover, the perception of care professionals and informal caregivers on trusting the patient could have been based on the patient's (non)verbal cues. Kramer (1996; 2004) suggests that care providers act as "intuitive auditors" when assessing a patient's behaviour. Their assessment could be based on two dimensions of trust that are similar to a patient's assessment of trust in their care provider (Hall et al., 2001). These two dimensions are: honesty (patients expressing benign motives, acting cooperatively and describing situations without exaggeration or ignoring relevant facts), and competence (assertiveness, compliance with directives, and identifying and providing relevant information) (Kramer & Cook, 2004; Pelaccia et al., 2016; Rogers, 2002). Therefore, the care providers in this study could have picked up on non-verbal cues in their daily interactions with an elderly patient, which could explain their level of trust in that patient.

Research into other concepts such as reporting pain and self-efficacy suggests that (elderly) patient and care provider characteristics could influence the level of alignment. However, contradictory results can be found with regard to which characteristics significantly influence alignment and whether misalignment can be attributed to lower or higher scores for the elderly patient or care provider (Green, Wells, & Laakso, 2011; Hoth et al., 2007; Li & Loke, 2014; McCarthy & Lyons, 2015; Porter et al., 2002; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2004). For example, various studies show that the severity of the patient's health condition is related to misalignment between elderly patients and informal caregivers, but this could mean that (elderly) patients or informal caregivers either overestimate or underestimate the situation (Hoth et al., 2007; Porter et al., 2002). Our study, for example, suggests a worse health condition of elderly patients in triads with misalignment if informal caregivers have a higher level of trust than the patient's view of their own behaviour. This suggests that specific elderly patient and care provider characteristics could explain the alignment level. However, given the contradictory findings of other studies, future research is necessary to explore in depth which elderly patient and care provider characteristics influence trust and the relationship between those characteristics and the alignment categories.

Relationship between trust in patients and self-management

The second aim of this study was to explore the relationship between care providers' trust in elderly patients and the patient's management of their own health. In the triads, the level of trust of the informal caregiver and the nurse in the elderly patient was unrelated to the patient's self-rated ability to self-manage, but did relate to their own perceptions of the patient's self-management behaviour. This study shows that informal caregivers view the patient's self-management ability more positively when their level of trust in the patient aligns with the level of trust of the nurse.

Firstly, it is important to mention that the lack of relationship between trust in elderly patient and the patient's self-rated self-management behaviour could be explained by the fact that the latter is determined not only by the quality of the relationships between elderly patients and care providers, but also by patient-specific characteristics such as state of health or financial situation (Barlow et al., 2002; Newman, Steed, & Mulligan, 2004),

Secondly, from a relational point of view, the explanation could lie in a gap between intrinsically *believing* in trusting a patient and *expressing* that trust. Communication is crucial for trust building and being open and honest could help generate trust between individuals (Calnan & Rowe, 2008). Research indicates that the extent to which patients experience trust from their care providers influences the trust they have in their own competence (Kramer & Cook, 2004; Thorne & Robinson, 1988; Wilk & Platt, 2016). Becker & Roblin (2008) showed that relationships with formal primary care providers who the (elderly) patient perceives as honest and supportive are associated with better self-management, while relationships that are perceived as unsupportive or strained lead to worse self-management. Trusting, therefore, demonstrates caring for the patient as a person. More importantly, care providers need to tell their patients that they believe they can indeed manage their health. Inspiring an optimistic attitude can boost a patient's confidence in their ability to manage their health (Gabay, 2015; Kramer & Cook, 2004).

Study limitations

When interpreting the results, careful consideration must be paid to the following. First, due to the cross-sectional design, we cannot draw conclusions on the causality between the informal caregivers' and nurses' levels of trust in the elderly patient's behaviour and the patient's view on their own behaviour. Also, we cannot draw conclusions on the causality between the levels of trust in the patient and the patient's self-management of their health.

Second, the relatively low number of triads in this study could be a limitation. However, this study aimed to explore the under-researched topic of care providers' trust in elderly patients and was intended to provide initial insight into the concept from three perspectives, as well as the relationship of trust to elderly patients' self-management ability.

Third, because we focused on analysing triads, the elderly patients were nested in with the informal caregivers and nurses. We are aware that multilevel analysis is commonly used with nested data. Unfortunately, due to our small sample size, we were unable to perform such analysis. However, given the difficulty of collecting data from elderly patients – face-to-face interviewing was necessary – we believe our study still provides a good first insight into a relatively new research topic for a relevant study group.

Fourth, careful consideration must be taken in the generalizability of our results. Though elderly patients were initially sampled at random by the home care organization, the final study sample could be biased as it depended on the elderly patient's consent to sharing their contact details and participating in the study. As a result, informal caregivers and nurses were sampled non-randomly. Because of this, the sample possibly does not represent all types of respondents, ignoring ethnic diversity, which could have affected our results. For example, Suurmond et al. (2016) and Wezel et al. (2016) show that specific ethnic groups (e.g. Turkish persons) often have a strong informal care network and use less home care. Also, EQ-5D-3L utility scores for elderly patients were significantly lower than the Dutch population norms.

Fifth, since 18 nurses filled in different questionnaires, it is possible that these nurses unknowingly compared patients, which could have affected their scoring. Nonetheless, our study specifically focused on analysing triads rather than unconnected groups of individuals in order to analyse the interpersonal character of trust. Therefore, non-random sampling was necessary.

Sixth, Cronbach's alphas of the adapted elderly patient version of the Physician Trust in the Patient Scale were relatively low, which could be due to the relatively few elderly patients participating in the study. However, Cronbach's alphas were high for the informal caregiver and nurse questionnaires, suggesting that the scale is reliable. Seventh, the significant relationships found in the care provider's level of trust and their view of the patient's selfmanagement ability might be slightly overestimated due to common source bias. However, the correlations were relatively low, suggesting that this bias had only a minor effect.

Implications

As both alignment and misalignment occur in triads, this study suggests that building and maintaining trusting relationships between elderly patients, their informal caregiver and the nurse is vital. Following relational coordination theory (Gittell, 2002; Weinberg, Lusenhop, Gittell, & Kautz, 2007), the quality of communication between individuals could positively affect the quality of their mutual relationships, and vice versa, and both could be supported by organising informal meetings to discuss mutual expectations regarding the patient's behaviour and mutual trust levels (Hartgerink et al., 2014). Such discussions could form part of the regular meetings on an elderly patient's care plan.

It is challenging to build a trusting relationship between a patient and a specific nurse, or between an informal caregiver and a nurse because home care is often delivered by a team of nurses (Weman & Fagerberg, 2006; Wiechula et al., 2016). Therefore, we suggest that home care organisations should try to limit the number of nurses delivering care to one patient and ideally should strive to pair patients and nurses, although we realise this is not always feasible in practice.

Expressing trust in patients is important and this value should be reflected in the attitudes and actions of informal caregivers and nurses (Kim et al., 2004; Wiechula et al., 2016). To achieve this, we suggest that nurses could benefit from 'compassionate assessment' ses-

sions, in which a group of nurses, guided by a trainer, reflect on building relationships with patients and informal caregivers (Adam & Taylor, 2014; Wiechula et al., 2016). Compassion is central to how people perceive care through relationships based on empathy, respect and dignity and primarily involves being aware of someone's feelings and interacting with them in a meaningful way (Dewar, Pullin, & Tocheris, 2011). Expressing compassion in a caring relationship could enhance a feeling of being trusted by another person (LoCurto & Berg, 2016) and compassionate training could help nurses to express their compassion towards elderly patients more explicitly (Adam & Taylor, 2014; Dewar et al., 2011). Though this type of training is usually for student nurses (Adam & Taylor, 2014), it could help more experienced nurses as it would enable them to reflect on their own behaviour (Gould et al., 2018). Nurses who have had this training might also be better able to assess and discuss the informal caregiver's attitude and behaviour towards the patient.

This study took a first step in exploring the level of trust that informal caregivers and nurses have in elderly patients. Future research could take the next steps. First, longitudinal studies, observing elderly patient-care provider interactions over time, could produce useful insight into how trust develops in daily practice (LoCurto & Berg, 2016). Second, future studies could look at the trust levels of other care providers (general practitioners, physiotherapists) and social network members (family members and friends), as elderly patients often receive care from many individuals whose (social) support has an impact on their self-management ability (Doekhie, Buljac-Samardzic, Strating, & Paauwe, 2017; Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016; Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014). Regardless of the type of research, future studies should consider that studying trust may lead to ethical issues between individuals, for example distrust. Although our study did not identify distrust between respondents, Kramer and Cook (2004) show that it can occur between patients and care providers, making it important to take into account when conducting research on trust.

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CHAPTER 6

Elderly patients' decision-making embedded in the social context. A mixed-method analysis of subjective norms and social support

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ABSTRACT

Background: Older patients are increasingly encouraged to be actively involved but how they perceive their role in the decision-making process varies according to their health care providers and their health situation. Their role could be influenced by their social context but more specifically by subjective norms (i.e. patients' view of the role that significant others expect them to play in the decision-making process) and perceived social support. We explore how social context (i.e. subjective norms and social support) relates to how the patient perceives their role in the decision-making process. Also, we explore the level of alignment on subjective norms between patients and their informal caregivers and nurses.

Methods: Mixed-method study among older patients, informal caregivers and nurses. For the quantitative questionnaire, a home care organisation randomly selected patients. The patients were asked to identify their informal caregiver and the home care organisation was asked to identify the nurse who was most involved in their care. In total 133 patients, 64 informal caregivers and 72 nurses were questioned. Participants for the qualitative interviews were selected using convenience sampling, resulting in the inclusion of ten patients, five informal caregivers and six nurses. Subjective norms were based on a previous study. Social support was measured with the 'social support for health scale' of the Health Literacy Questionnaire. The Control Preference Scale was used as outcome variable. The interviews focused on subjective norms, social support and how the patient perceived their role. Quantitative analysis included the calculation of subjective norm difference scores between respondent groups, one-way analysis of variance and multinomial logistic regression analysis. Directed content analysis was applied to the interviews using Atlas TI.

Results: Lower difference scores were found for patient-informal caregiver dyads (mean = 0.95), implying more alignment than in patient-nurse dyads (mean = 2.12). Patients perceiving themselves to have a shared or passive role tend to believe that they are expected to leave decision-making to the health care provider. Higher social support scores related more to a shared role. Alignment relates to: familiarity with the patient's preferences, overprotective-ness or valuing the care provider's opinion and the severity of the patient's medical history.

Conclusion: Patients and informal caregivers align on whether the patient should make decisions. The more patients believe that they are expected to leave decision-making to the health care provider, the more they perceive themselves as having a passive role. The more patients who feel they have support, the more they perceive themselves as having a shared role. Patients and caregivers could be facilitated to make role expectations explicit. Examining support resources in the social network is desirable.

INTRODUCTION

Health care providers are urged to actively involve older patients in the decision-making process (Chewning et al., 2012; Jahng, Martin, Golin, & DiMatteo, 2005; Say, Murtagh, & Thomson, 2006; Thompson, 2007). Research shows that patients vary in their degree of involvement as they take on various roles in the decision-making process (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Chewning et al., 2012; Elwyn et al., 2001; Flynn, Smith, & Vanness, 2006; Moreau et al., 2012; Thompson, 2007). Some prefer to make decisions themselves, some prefer others to make decisions for them and some want to share the responsibility with others (e.g. the care provider) (Degner, Sloan, & Venkatesh, 1997; Thompson, 2007).

The influence of patient characteristics (e.g. educational level) on the patients' role in decision-making and the quality of the patient-care provider relationship have been widely studied (Bastiaens et al., 2007; Chewning et al., 2012; Edwards, Davies, & Edwards, 2009; Flynn et al., 2006; Jabbour et al., 2018; Moreau et al., 2012; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009; Thompson, 2007), but few studies have focused on the influence of social context on the patient's role (Brabers, van Dijk, Groenewegen, & de Jong, 2016; Burke, Joseph, Pasick, & Barker, 2009; Ommen, Thuem, Pfaff, & Janssen, 2011; Pasick & Burke, 2008; Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016). This is important, however, as patients are often supported in their decision-making by a closely-related companion (informal caregiver) (Isenberg et al., 2018; Laidsaar-Powell et al., 2013; Wolff, Clayman, Rabins, Cook, & Roter, 2015; Wolff et al., 2017). In situations where patients perceive themselves to be involved, the presence of companions could affect the patient's role in different ways, both positively and negatively. For example, companions can activate the patient and enhance their autonomy by adopting a supportive role in clarifying information (Wolff et al., 2017), or hinder patients by being too dominant, causing patients to become passive and less involved than they would like (Laidsaar-Powell et al., 2013).

Social context in relation to health is often conceived as a multifaceted construct that may be defined as "*the sociocultural forces that shape people's day-to-day experiences and that directly and indirectly affect health and behaviour*" (Burke et al., 2009; Pasick & Burke, 2008). These forces include organisations, such as schools or communities, and individuals, such as family or friends and both types can influence individuals' behaviour in ways they are not always aware of (Burke et al., 2009). This study focuses on two concepts in the second type of social forces that influence patients' roles in the decision-making process: subjective norms and perceived social support. Subjective norms are considered a social norm and refer to the perceived support, pressure or the expectations of persons considered important, such as informal caregivers (Burke et al., 2009; de Vries, Dijkstra, & Kuhlman, 1988; van Hooft, Dwarswaard, Bal, Strating, & van Staa, 2016). In practice, subjective norms lead patients to act in a way they believe is expected of them by a significant other (Brabers et al., 2016). CHAPTER 6

This implies that when patients feel that they are expected to leave decision-making to the care provider, they are more likely to do so. To our knowledge, only one study has focused on subjective norms in relation to patient involvement; it shows that the patient's subjective norms affect the patient's involvement in the decision-making process (Brabers et al., 2016).

Building on Brabers and colleagues (2016), our study not only explores the relationship between subjective norms and the patient's role, but also the level of alignment regarding the subjective norms between a patient and two individuals within the patient's (care) network: the informal caregiver and home care nurse. Older patients often have an ongoing caring and trusting relationship with a nurse due to the longevity of chronic care delivery (Lindahl, Lidén, & Lindblad, 2011; Wiechula et al., 2016). This relationship makes it likely that patients' subjective norms regarding the nurses' expectations could influence their own perceived role in the decision-making process. We explore how patients' expectations of how their informal caregiver or nurse think they should act aligns with the latter two individuals' perspective on the patient's role in the decision-making process. This is important as research on the role of family companions in consultations reveals little alignment between patients and companions regarding expectations of the patient's role (Shin et al., 2013; Shin et al., 2017; Wolff et al., 2017), suggesting a similar misalignment with regard to subjective norms.

The second relevant concept in this context is social support, which can be defined as "*the perception or experience that one is loved and cared for, esteemed and valued, and part of a social network of assistance and mutual obligations*" (Wills, 1991). O'Reilly (1988) defines a social network as "*an analytical concept, used to describe the structure and linkages between individuals or groups of individuals*". Therefore, the concept of social networks refers among others to the density and dispersion in the network (Due, Holstein, Lund, Modvig, & Avlund, 1999). This concept consists of two dimensions (O'Reilly, 1988). Firstly, the structure dimension, which includes the frequency of social contact (e.g. visiting or phoning family members) and the types of individuals in the network. Secondly, the function dimension, which refers to the social support within a network. Social support can be divided into four types: (1) emotional support (e.g. empathy and love), (2) instrumental support (i.e. the provision of tangible goods, e.g. helping a patient get to the hospital), (3) informational support (i.e. providing information, e.g. feedback) (Langford, Bowsher, Maloney, & Lillis, 1997).

Research on social support mainly focuses on the relationship to self-management, indicating that social support could enhance a patient's self-confidence level to cope with their condition (Dwarswaard, Bakker, Staa, & Boeije, 2016; Gallant, 2003; Koetsenruijter et al., 2014; Reeves et al., 2014). Hobbs and colleagues (2015) looked at the relationship between social support and patient role, showing that patients perceiving high levels of social support are more likely to share in the decision-making process with family members and the care provider.

The research question of this study is: *How do subjective norms and social support influence the elderly patient's perceived role in the decision-making process?*

METHODS

We conducted a mixed-method study in the Netherlands. Because elderly patients may suffer from multiple chronic conditions and are in contact with many different, health care providers (e.g. general practitioners, home care nurses) (Doekhie, Buljac-Samardzic, Strating, & Paauwe, 2017), the types of decision and the decision-making process may vary. For that reason, we did not focus on a specific type of decision or specific type of health care provider. Rather, we broadly examine the decision-making process of elderly patients regarding their general health situation in relation to the health care providers most involved in their care.

We first surveyed a cross section of older people receiving home care from one large home care organisation, the patient's informal caregivers and their most involved nurse. Patients were included if they were 60 years or older. Informal caregivers were family members (e.g. children), close friends or neighbours who provided non-professional, unpaid care (Janse, Huijsman, Looman, & Fabbricotti, 2018).

To gain a deeper understanding of these concepts in daily life and to better understand the context of the quantitative results, we then conducted semi-structured interviews with patients, informal caregivers and nurses other than the survey respondents. The aim was to gain deeper insight into the relationships between these three groups in daily life, particularly how expectations about how a patient should act (subjective norms) and social support shape the patient's perceived role in the decision-making process.

Quantitative data collection

Figure 6.1 illustrates the data collection process. The home care organisation randomly sampled 2000 older people and sent them an informed consent letter. The research team only contacted those who returned a signed consent form. For privacy reasons, background information on non-responders was not available to the research team.

Trained interviewers visited all the patients (older people) at home. The structured interview involved reading aloud the items and answer options of the questionnaire. Patients were asked to select one of the options and given the opportunity to elaborate on their answers, thus providing the researchers with deeper insight into the patients' reasoning for a high or low score. All interviews were audio-taped.

Patients were asked to identify their informal caregiver and invited to forward a questionnaire for the informal caregiver to fill in, together with an information letter. In total, 94 informal caregivers received the questionnaire. The questionnaires for the nurses, including an information letter stating the name of the patient concerned, were distributed through their team leaders. In total, 114 nurses received a questionnaire, including 17 nurses who received two questionnaires and one nurse who received three questionnaires for different patients. The final sample consisted of 133 patients, 64 informal caregivers and 72 nurses.



Final study population

(informal carers)

n=64

39 triads of older persons informal carers and home care purses

Loss to follow-up (n=42)

Refused to participate

(n=42)

Final study population (home

care nurses)

n=72

Figure 6.1. Quantitative data collection flow chart

Deceased (n=3)

Qualitative data collection

Final study population (older

persons)

n=133

Convenience sampling within the researchers' own network was used to select participants. Elderly patients are a difficult group in which to find enough participants who are willing and able to participate. Convenience sampling proved an appropriate method to find enough participants for this study. Participants were contacted in person or by telephone and informed of the study aims, asked explicitly for consent to the interview and told that they were free to withdraw from the study at any time. All participants gave their permission to use quotations from the interviews. All interviews took place at the participant's preferred location and lasted between 30 and 60 minutes. A total of ten patients, five informal caregivers and six nurses were interviewed. The data collection period consisted of multiple phases and should be seen as an iterative process. In the first phase, convenience sampling was used which resulted in the conclusion of four patients, two informal caregivers and three nurses. During this phase, the interview guide was piloted. In phase two, the interview transcripts were by the primary researcher in light of the three key concepts of this study (i.e. subjective norms, social analysed support and patient's roles in the decision-making process) using Atlas TI. The codes and corresponding quotations showed great variety, suggesting that data saturation had not yet been reached. Therefore, in phase three, convenience sampling was again used to include more participants, leading to the inclusion of another six patients, three informal caregivers and three nurses. In phase four, the new transcripts were added to Atlas TI and coded. During this phase, no new information was found, suggesting that data saturation had been reached. In phase five, the codebook was discussed with the research team and themes were discussed until consensus was reached. Table 6.1 presents the characteristics of the participants.

-	* *		
	Patients (n=10)	Informal caregivers (n=5)	Home care nurses (n=6)
Gender			
Female n (%)	7 (70%)	4 (80%)	6 (100%)
Male n (%)	3 (30%)	1 (20%)	0 (0%)
Age mean (range)	85.4 (77-93)	50.6 (39-66	45.8 (32-54)

Table 6.1. Qualitative interviews - participant characteristics

The primary researcher (KD) developed the topic list and interview guide based on insights derived from literature on a patient's role in decision-making and social networks, which were revised following input from the entire research team. All semi-structured interviews were conducted by the primary researcher. The semi-structured interviews started with the interviewer explaining the aim and explicitly asking for verbal consent to audio-recording. The interviews with patients addressed three topics: (A) expectations regarding who should make decisions (subjective norms), (B) the patient's social network, specifically the structural dimension (i.e. types of individuals and frequency of contact) and the functional dimension (i.e. social support) and (C) the patient's perceived role in the decision-making process. The interviews with informal caregivers and nurses focused on topics A and C. All participants were asked to illustrate their answers from real-life situations. Table 6.2 provides insight into some of the questions posed in the interview guide.

Questionnaire

Socio-demographic characteristics

Respondents were asked to report on various background characteristics, including age, gender and educational level. Patients' health status was measured with the validated fivedimensional, three-level EuroQol instrument (EQ-5D-3L) and the EuroQol visual analogue scale (EQ VAS) (Szende, Janssen, & Cabases, 2014).

Subjective norms

The subjective norms in this study, following Brabers and colleagues (2016), focused on what the patient thought their informal caregiver or nurse expected of them in medical decision-making.

Two sets of two questions were included in the patient questionnaire (table 6.3). Mean scores for each set were calculated and the higher the score, the more the patients thought that their informal caregiver and/or nurse expected them to leave decisions to the care provider.

The two questions on subjective norms were rephrased in the informal caregiver and nurse questionnaires to measure their view on how the patient should act. Mean scores were calculated and the higher the score, the more the respondent thought that the patient should leave decisions to the care provider.

		Questions	
Topics	Patients	Informal caregivers	Home care nurses
A. Expectations regarding who should make decisions	 Who do you think should make the decisions about your (health) situation according to your informal caregiver? Have you ever discussed what is best for your health with the home care nurse? If so, what do you believe is their opinion on who should make decisions regarding your situation? 	1. Who do you believe should make decisions about your significant others (health) situation?	1. Who do you believe should make decisions about the patient's (health) situation?
B. Patient's social network	 Could you describe the persons you believe are part of your social network? What kind of support do these persons provide to you? 		
C. Patient's preferred role in the decision- making process	 Could you describe how decisions regarding your health situation are usually made? Do you prefer to discuss to decisions regarding your health situation with your informal caregiver? If so, could you give an example of how you discussed this? 	 What role you do see for yourself in the decision-making process regarding the health situation of your significant other? How capable do you believe your significant other is to independently make decisions? 	 Do you find it important that patients make their own decisions? If so, please explain why. How capable do you believe the patient is to independently make decisions?

Table 6.2. Main interview topics and questions

Social support

In the patient questionnaire, perceived social support was measured with one of the validated scales of the Health Literacy Questionnaire (HLQ): the 'Social support for health' scale (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) (table 6.3). The HLQ addresses health literacy as a multidimensional concept, covering nine distinct dimensions of health literacy. Each scale of the HLQ should be seen as an individually validated scale instead of a sub-scale and may be used separately as long as all scale items are included (Osborne et al., 2013). The higher the score, the more social support a patient feels they have.

Outcome measure: patient role in decision-making

In the patient questionnaire, the patient's perceived role was measured with the Control Preference Scale (Degner et al., 1997; Katz et al., 2005; Lantz et al., 2005). Patients were asked to choose the statement that best described how decisions regarding their health situation were made (table 6.3). Older patients suffer from different chronic conditions and may therefore require different treatments. As we did not focus on a specific patient group, the patient's perceived role in decision-making was not assessed with regard to a specific decision involving one disease or condition. Rather, we asked patients how decisions were generally made with respect to their health condition.

Questions	Answer categories	Reliability scale
A. Subjective norms		
Patient questionnaire ^a	Strongly agree (1), Agree (2), Undecided (3), Disagree (4), Strongly disagree (5)	
1. My informal caregiver thinks that I should let the health care provider decide what is best for my health. My informal caregiver would prefer that to my having to make a choice.		Cronbach's alpha 2 items: 0.82
2. My informal caregiver thinks that the most important health decisions should be made by the health care provider and not by me.		
3. My home care nurse thinks that I should let the health care provider decide what is best for my health. My home care nurse would prefer that to my having to make a choice.		Cronbach's alpha 2 items: 0.83
4. My home care nurse thinks that the most important health decisions should be made by the health care provider and not by me.		
Informal caregiver and home care nurse questionnaires	Strongly agree (1), Agree (2), Undecided (3), Disagree (4), Strongly disagree (5)	Informal caregiver questionnaire: Cronbach's alpha: 0.81. Principal component analyses: all items loaded onto one factor;
1. I believe the patient should let the care provider decide what is best for their health. I would prefer that to the patient making that choice.		eigenvalue of 1.69 (84.38% variance explained)
2. I believe the most important health decisions should be made by the care provider and not by the patient.		Nurse questionnaire: Cronbach's alpha: 0.82 Principal component analyses: all items loaded onto one factor; eigenvalue of 1.70 (84.77% of the variance explained)
B. Social support		
Patient questionnaire	Strongly disagree (1), Disagree (2), Agree (3), Strongly agree (4)	Cronbach's alpha: 0.86 Principal component analyses:
I can get access to several people who understand and support me.		all items loaded onto one factor; eigenvalue of 3.25, explaining 64 96% of the variance
When I feel ill, the people around me really understand what I am going through.		
If I need help, I have plenty of people I can rely on.		
I have at least one person who can come to medical		

Table 6.3. Items of the questionnaires

appointments with me.

I have strong support from my family and friends.

C. Involvement in decision-making (Control Preference Scale)

Patient questionnaire

- 1. I make the decision about the care I receive.
- 2a. I make the final decision about my care after seriously considering my informal caregiver's opinion.
- 2b. I make the final decision about my care after seriously considering my health care provider's opinion.
- 3a. My informal caregiver and I share responsibility for deciding what type of care is best for me.
- 3b. My health care provider and I share responsibility for deciding what type of care is best for me.
- 4a. I leave all decisions regarding my care to my informal caregiver.
- 4b. I leave all decisions regarding my care to the health care provider.
- 5a. My informal caregiver makes the final decision on I will get, but seriously considers my opinion.
- 5b. The care provider makes the final decision about what type of care I will receive, but seriously considers my opinion.

^a Principal component analysis revealed that all four items loaded onto one factor, with an eigenvalue of 3.03 (75.75% of the variance explained), suggesting that all four items could be taken together on one scale. Cronbach's alpha of the four items is 0.89.

Originally, the statements only reflected on the possible role of the medical specialist in the decision-making process (Degner et al., 1997). The statements were adapted to focus on the health care provider in general and to include the possible role of the informal caregiver (table 6.3). This modification to the scale, the addition of the informal caregiver, has been applied in other research on the role of significant others in the decision-making process (Kunneman et al., 2017; Shin et al., 2017; Walczak et al., 2017). During the structured interviews with the patients, the different options were also discussed and respondents were explicitly asked whether they had understood all options.

The statements covered three perceived patient roles in the decision-making process: (a) an active role (statements 1 and 2, a and b), (b) shared role (statement 3, a and b) and (c) a passive role (statements 4, a and b, and 5, a and b) (Florin, Ehrenberg, & Ehnfors, 2006; Jabbour et al., 2018; Singh et al., 2010). Consistent with other research, decision-making scores were collapsed into three types of patient roles by combining the first two active statements, the last two passive statements and the third statement alone (Brom et al., 2014; Degner et al., 1997; Jabbour et al., 2018; Say et al., 2006). These are: an active role (i.e. patients who want to be heavily involved in the decision-making process), a shared role (i.e. patients who want to make decisions together with their informal caregiver and/or care provider on an equal basis) and a passive role (i.e. patients who want their and a passive role (i.e. patients who want tal., 2018; Say et al., 2012; Jabbour et al., 2018; Say et al., 2012; Jabbour et al., 2018; Say et al., 2012; Jabbour et al., 2018; Say et al., 2016).

Data analyses

Quantitative data were analysed with IBM SPSS 25.0. Descriptive statistics were completed for all variables. All analyses were discussed and planned a priori to the data collection by the research team.

Regarding subjective norms, we first analysed the level of alignment between what the patient thought the informal caregiver or nurse expected from them and the views of the latter two groups on how the patient should act by calculating difference scores between patient and informal caregiver, and patient and nurse. Difference scores could only be calculated when both patient and informal caregiver or nurse had answered the subjective norm questions. Difference scores between patient and informal caregiver were calculated by the subjective norm sum score of the patient minus the subjective norm sum score for the informal caregiver on all items. Difference scores between patient and nurse were calculated in a similar manner. A positive difference score implied that patients more often felt that their informal caregiver or nurse expected them to leave the decision to the care provider, while the latter two groups believed that the patient should make the decision themselves. A difference score of zero suggests complete alignment between two groups. Pearson correlations were calculated to investigate the relationship between the subjective norm scores of the three respondent groups.

Next, the relationships between subjective norms and social support and the categorical outcome measure (three roles in decision-making) were analysed in two ways. First, one-way analysis of variance (ANOVA) followed by a Bonferroni post-hoc test was performed to compare the mean subjective (differences) and social support scores between the three perceived patient roles in decision-making. A multinomial logistic regression analysis was then performed to further examine the relationship between the variables. Because the subjective norms from the patient's perspective loaded onto a single factor in the principal component analysis and the multicollinearity between both variables, the patients' scores for the expectations of both informal caregivers and nurses were merged into one variable 'patients' subjective norms' for the regression analysis. The audio tapes of the conversations with the patients were transcribed verbatim with regard to the questions on subjective norms, social support and perceived role in decision-making. Based on a patient's questionnaire score, the quotes were categorised in high or low subjective norm and social support score and for all three patient's roles.

The qualitative interviews were audio-taped, transcribed verbatim and analysed using Atlas TI. A directed content analysis method was applied, using the three key concepts of this study as a guideline for initial categorical coding by the primary researcher (Hsieh & Shannon, 2005). The content of each category was then sorted further according to existing theory (Hsieh & Shannon, 2005). For example, quotes on the patient's perceived role in the decision-making process were categorised as an active, shared or passive role and combined in the theme patient's role in the decision-making process. This produced the following analytical themes: (a) familiarity, (b) care provider knows best, (c) patient's medical history, (d), patient-informal caregiver relationship, (e) support from social network, (f) patient's role in the decision-making process. Next, the themes were discussed in the research team and combined and analysed in the light of the literature on subjective norms, social support and

patient's role in the decision-making process until consensus was reached. This produced the following themes guiding the results section: (a) underlying factors in the patient-informal caregiver/home care nurse relationship, (b) networks of multiple support circles, (c) implicit and explicit patient role expectations.

Transcripts of the interviews, together with the audio recordings of the questionnaires provided deeper insight into the concepts from the respondents' perspectives and were used for the qualitative results section.

RESULTS

Quantitative results

Sample characteristics respondents

Patient participants (n=133) were on an average 81.1 years old, 64.7% were female, 89/133 had an informal caregiver and 55.1% received care from children (in law). This is comparable to the general Dutch population in that most home care recipients are female and receive informal care from their children (table 6.4) (Klerk, Boer, Plaisier, & Schyns, 2016). Patients rated their health status as average (EQ-5D-3L = 0.55; EQ VAS = 57.48). Both EQ scores were statistically significantly lower than Dutch population norms (t = -11.14, p < 0.05 and t = -15.59, p < 0.05 respectively) (Szende et al., 2014).

Informal caregivers were on an average 64.1 years old, 65.1% were female and 48.4% provided care for their parent (in law), which again is comparable to the Dutch population in that most informal caregivers are female (56%) and 42% provide care for their parent (in law) (Klerk et al., 2016). Nurses were mostly female (98.6%) and 63.4% had been caring for their patient for between one and three years.

Subjective norms and social support

Table 6.5 shows the mean scores for subjective norms for all respondent groups (whole sample included) and social support. The difference subjective norm scores were calculated between patient and informal caregiver and between the patients and the nurse. A lower mean difference score was found for patient-informal caregiver dyads (mean = 0.95) than for patient-nurse dyads (mean = 2.12), implying better alignment between patient and informal caregiver on what type of behaviour the patient thinks that the informal caregiver expects of them and the latter's ideas on how the patient should act, than between patient and nurse.

Correlation analysis of the subjective norms was in line with the difference scores, showing a moderately significant correlation between patient and informal caregiver subjective norm scores (r = .34, p < 0.05). Although a larger correlation was found between patient and nurse, this was not significant (r. = .58, p > 0.05).

	Patien	ts	Informal c	arers	Home care r	urses
-	Ν	%	Ν	%	N	%
Age (mean, SD)	81.1 (8.6)		64.1 (13.8)		45.8 (11.0)	
Sex						
Male	47	35	22	35	1	1.4
Marital status						
Married	36	27	45	71		
Unmarried	11	8.3	6	9.5		
Divorced	16	12	4	6.3		
Widow(er)	67	50	5	7.9		
Registered partnership	3	2.3	3	4.8		
Educational status						
Less than high school	48	37	11	18	0	0
High school/technical school	73	56	44	71	69	96
College and above	10	7.6	7	5.3	3	4.2
Living status						
Alone	94	71	12	9		
With partner	36	27	40	64		
With partner and children	1	0.8	8	13		
With children	2	1.5	1	1.6		
Co-resident informal carer	28	21.05				
Ethnic background						
Dutch	128	96.2	57	42.9		

Table 6.4. Quantitative questionnaire - respondent characteristics

Table 6.5. Mean and difference scores on subjective norms and social support

Variables	N	Mean (SD)	Range
			(min –max)
Subjective norms in decision-making			
Patients' score on what informal caregiver expects of them	88	3.87 (1.30)	1.005.00
Patients' score on what home care nurse expects of them	118	3.86 (1.17)	1.00 - 5.00
Informal caregivers' view on how patient should act	62	3.42 (1.34)	1.005.00
Home care nurses' view on how patient should act	73	3.06 (1.25)	1.00 - 5.00
Difference scores subjective norms			
Patient – informal caregiver	61	0.95 (3.01)	-8.00 - 8.00
Patient – home care nurse	66	2.12 (3.42)	-5.00 - 8.00
Social support (patient self-reported)			
Patients' score	132	2.87 (0.65)	1.00 - 5.00

Relationship between subjective (difference) scores, social support and patient role in decision-making

Overall, 56 patients (42.7%) perceived themselves as having an active role, 54 patients (41.2%) a shared role and 21 patients (16.0%) a passive role in the decision-making process.

One-way ANOVA (table 6.6) first revealed significant differences between the three patient groups regarding the patient's subjective scores on what they thought that the informal caregiver expected of them (F=6.79, p = 0.002) and the nurse (F=8.53, p = 0.000). The posthoc Bonferroni test revealed that for both subjective norms, patients perceiving themselves as having a shared role or passive role reported significantly higher mean scores than the patients perceiving themselves as having an active role. This means that patients perceiving themselves as having a shared or passive role are more likely to believe that their informal caregiver or nurse expects them to leave the decision to the care provider. Moreover, significant differences were also found in patient self-rated social support mean scores between the three patient roles (F=4.22, p = 0.017). Patients with the lowest level of support also perceived themselves as having a passive role in decision-making, whereas patients with the highest level of support perceived themselves as having a shared role. Patients who perceive themselves as having an active role reported a slightly higher level of support than patients who perceive themselves as having a passive role, but not higher than patients perceiving themselves as having a shared role. Bonferroni post-hoc test revealed a relatively significant difference between active and shared role (p = 0.056).

	A	Active role	S	hared role	Р	assive role		
	N	Mean	Ν	Mean	Ν	Mean	F (d.f)	Р
		(SD)		(SD)		(SD)		value
Subjective norms								
Patients' score on what informal caregiver expects ^a	36	3.32 (1.40)	39	4.14 (1.16)	13	4.58 (0.76)	6.79 (2)	0.002
Patients' score on what home care nurse expects $\ensuremath{^a}$	51	3.38 (1.25)	48	4.19 (0.99)	19	4.32 (0.93)	8.53 (2)	0.000
Informal caregivers' view on how patient should act	24	3.17 (1.35)	28	3.39 (1.38)	10	4.10 (1.07)	1.76 (2)	0.180
Home care nurses' view on how the patient should act	25	2.82 (1.10)	33	3.17 (1.38)	13	3.12 (1.19)	0.574 (2)	0.566
Difference scores subjective norms								
Patient – informal caregiver	24	0.63 (3.46)	28	1.21 (2.70)	9	1.00 (2.87)	0.243 (2)	0.785
Patient – home care nurse	23	1.48 (3.45)	30	2.63 (3.22)	13	2.08 (3.86)	0.739 (2)	0.482
Social support								
Patients' score	56	2.75 (0.64)	54	3.04 (0.59)	21	2.68 (0.69)	4.22 (2)	0.017

Table 6.6. One-way ANOVA on subjective norms, difference scores and social support per patient role

^a Bonferroni post-hoc test reveals significant differences between active role and shared role and between the active role and passive role

Based on the ANOVA, the statistically significant variables (i.e. subjective norms and social support) were used in the multinomial logistic regression (table 6.7). Patients' subjective norms regarding the expectations of both informal caregivers and nurses were merged into one variable 'patient subjective norms'. The model first shows that patients with a higher score for subjective norm (patients who think that their informal caregiver/nurse expects them to leave the decision to the care provider) are more likely to perceive themselves as having a passive role [OR = 2.92, 95% CI (1.24-6.87), p = 0.014] or shared role [OR = 2.05, 95% CI (1.24-3.40), p = 0.005] than an active role. Patients with a high level of social support are 3.8 times more likely to perceive a shared role than an active role [OR = 3.85, 95% CI (1.26-11.77), p = 0.018]. No significant differences were found for subjective norm scores in patients with a perceived active role and, regarding social support, in patients with a shared role compared to patients perceiving themselves as having a passive role.

	Active role			
	Rc – Shared		Rc – Passive	
Model				
Patient subjective norms	0.486 (0.294-0.804)	.005	0.342 (0.145-0.802)	.014
Perceived social support	0.259 (0.085-0.792)	.018	0.925 (0.221-3.873)	.915
	Shared role			
_	Rc – Active		Rc – Passive	
Model				
Patient subjective norms	2.058 (1.243-3.406)	.005	0.703 (0.296-1.670)	.425
Perceived social support	3.856 (1.263-11.773)	.018	3.567 (0.895-14.224)	.072
	Passive role			
_	Rc - Active		Rc - Shared	
Model				
Patient subjective norms	2.927 (1.246-6.876)	.014	1.423 (0.599-3.380)	.425
Perceived social support	1.081 (0.258-4.527)	.915	0.280 (0.070-1.118)	.072

Table 6.7. Multinomial regression analysis on subjective norms and social support

Note: Rc = Reference category

Qualitative results

Subjective norms: underlying factors in the patient – informal caregiver/nurse relationship

Whether or not patients think that their informal caregiver and/or nurse expects them to make the decision themselves or leave it up the care provider, and whether or not the latter two groups prefer the patient to make the decisions seems to be down to three factors: (a) familiarity, meaning how well the informal caregiver or nurse knows the patient's preferences; (b) valuing the care provider's opinion due to overprotection and reassurance; and

(c) the severity of the patient's (medical) history. Quote 1 (Table 6.8) illustrates the case of a patient who thinks their informal caregiver expects them to make the decision themselves because they know her well. Quote 2 illustrates the influence of the patient's medical history. In some cases, informal caregivers value the care provider's opinion but still want the patient to make decisions themselves. These informal caregivers sometimes try to steer the patient towards the care provider's advice, making them believe that they have made the decision themselves (quote 3). Also, nurses sometimes seek the help of the informal caregiver to steer a patient into another direction (quote 4).

Overprotectiveness or seeking reassurance from the care provider can cause misalignment between the patient and the informal caregiver or nurse in the sense of patients wanting to make decisions themselves, but the latter two taking over control (quotes 5 and 6).

Social support: networks of multiple support circles

Within the social networks of the participants, the types of individuals and the frequency of social contact and support vary (structural and functional dimensions of social networks). The networks of participants vary in size and types of individuals in the network. Social networks seem to consist of multiple circles surrounding a patient with a (dominant) informal caregiver in the circle closest to the patient, followed by a circle of family and friends (living close by) and a circle consisting of neighbours and social groups such as church members. In some cases, patients have no circles in their network. As a result, the frequency of contact with individuals and well as the perceived support is low (quote 7). In other cases, patients have numerous social contacts, mostly with their dominant informal caregiver(s) and perceive great support from their informal caregiver's circle (quote 8), or a moderate amount of support from all circles (quote 9). In most cases, support mainly entails emotional (e.g. love and affection) and instrumental support (e.g. helping the patient get to the doctor's office, helping with grocery shopping).

Notably, some patients with a high level of social support from informal caregivers appreciate the support but sometimes feel it is too much and want to be left alone (quotes 10 and 11).

Patient's role in the decision-making process: implicit and explicit patient role expectations

Most patients who perceive themselves as having an active role expressed being open to other's opinions but valued taking the final decision themselves (quote 12). These patients mostly feel that they know best what care or treatment is best for them. In some cases, nurses or informal caregivers also feel that patients should make the final decision, even if they do not always agree (quotes 13).

Most patients perceiving themselves as having a shared role said that they talk to their informal caregiver (often a partner or children) first and prefer taking decisions together.

Subjective norms	
Quote 1 (patient)	"She [informal caregiver] knows me. She knows her mother is not a pushover. She knows that I have something to say".
Quote 2 (informal caregiver)	"If I see that the cardiologist is right about something, that it's better for her [patient], I always try to make her see that and steer her into taking the cardiologist's advice. The idea is to have her believe that she made the decision herself. Because only if she believes she did will she feel good about it. So I play along with her so that she can stand behind the decision one hundred percent. I believe that's the best thing you can do."
Quote 3 (patient)	"In my case my wife [informal caregiver] always says: 'We must let the specialist decide' simply because I should already be dead. So the hospital told us to call at once if something is wrong."
Quote 4 (home care nurse)	"Once there was a lady with severe knee problems, but her bedroom was on the first floor. She could barely walk up the stairs. Her toilet was downstairs and she used it at least three times a night. So I said, "Why don't you move the bed to the living room and sleep downstairs?" She didn't want to hear a thing about that idea and refused. So I phoned her daughter [informal caregiver] and explained the situation. She visited her mother that evening and talked to her. The next day the bed was put in the living room."
Quote 5 (patient)	"My mind still works. I can make my own decisions. I'm always fighting for that. My sister [informal caregiver] thinks that I'm no longer capable of doing things for myself and tries to decide for me. But I'm not an idiot. Just because I'm old doesn't mean I'm an idiot."
Quote 6 (patient)	"If something is wrong with me, but I don't want to involve the general practitioner, she [informal caregiver] picks up the phone and calls the general practitioner straight away. The home care nurses always tell me to call the general practitioner. But I never do. So they call behind my back. They're worried about me."
Social network	
Quote 7 (patient)	"I'm old, but so are my children. They're all grandmothers and have their own families. So I cannot rely on them. [].I don't have many friends. Most of them are already dead. And most of my family were murdered in the Second World War. And my husband and his family are also dead. [] When I moved here 20 years ago everybody was my age. Now they're all dead or have moved away to their children or a different city. I'm the oldest person in this building. Everybody works so I am all alone here in daytime. I can ask my downstairs neighbour for help if needed, but he is not always home. So even though I have a roof over my head, if is very lonely."
Quote 8 (patient)	"I'm very grateful for the support of my three sweet daughters. When I hear my neighbour's stories about how his children treat him, I feel very thankful for their support. They help me with grocery shopping or go with me to visit the general practitioner. And they also keep me company, otherwise you'd be so lonely. I can't leave my house without them."
Quote 9 (patient)	"Some people find it easy to ask for help. I'm not really like that. My neighbour has a son and sometimes he helps me. The other day when it was cold and the roads were slippery, he put salt on the pavement in front of my house. My daughters [one of whom is the informal caregiver] live pretty far away, so I try to ask them for help as little as possible. I always go to my neighbour for help. He has my key in case anything is wrong."
Quote 10 (patient)	"I like it when my children visit me, but I'm also so glad when they leave. I have six children and the boys don't bother me. But when the girls come, they check the expiration dates of every product in my refrigerator. And they check if my clothes are put away neatly. They're like the police. Yes, people do support me, but sometimes it's a bit too much. One daughter acts like the Mother Superior of a convent. Everything goes through her. If something is wrong with me, they all know immediately." (70).
Quote 11 (patient)	"I'm happy they [children] visit me, but they don't need to come more often. Once a week is fine. I'm grateful for their support, but sometimes they interfere way too much. They always want to come with me to the general practitioner and always ask 'Have you done this or that?' They shouldn't be digging into my private life."

Table 6.8. Quotes on subjective norms, social support and patient's role in the decision-making process

Patient's role in the decision-making process		
Quote 12 (patient)	"I always make all my own decisions. Sometimes the children ask about my health. I listen to them, as long as their opinion does not conflict with my own. Because I do have my own opinion."	
Quote 13 (informal caregiver)	"I think it's most important that he [patient] makes the decisions. Put simply, if I do something against his will, he will definitely let me know. If he doesn't want something, it's not going to happen. No matter how I feel about it. And sometimes I think: I don't agree. But this is what you want, so be it."	
Quote 14 (patient)	"I always discuss everything with my two children. And if there's something serious, my daughter always says, 'Mom, I'll call the general practitioner for you'."	
Quote 15 (informal caregiver)	"She [patient] wants to be involved in decision-making, but I have to help her understand what the oncologist is saying. She can't hear very well and the oncologist doesn't always consider that. So I write things down and when we get home and she is all relaxed again, I explain it all again in simple terms. I always accompany her and write a short report which she can read afterwards."	
Quote 16 (patient)	"If the general practitioner tells me 'you should do this or that', I always listen. I didn't listen once and he got really mad. I had severe palpitations and he told me to go to hospital. But I went home first before going there. And he was really mad. So now I trust my general practitioner 100%."	
Quote 17 (informal caregiver)	"I usually make all the decisions, together with my wife [patient]. We decide what is best for her. You can't discuss things with her because she doesn't understand what is best for her anymore. She usually finds everything okay and never gets mad. She might say that she wants to eat something else, but that's about it."	

Table 6.8. Quotes on subjective norms, social support and patient's role in the decision-making process (continued)

Note: For privacy reasons, the quotes are not linked to a specific participant.

Both patient and informal caregiver involved the care provider if they felt this was necessary (quote 14). In some cases, patients felt that having an informal caregiver present at a medical consultation was useful for helping them remember information and asking questions, for example. Most informal caregivers expressed the importance of providing this support (quote 15).

Patients perceiving themselves as having a passive role relied heavily on either their care provider or informal caregivers to make decisions for them. In the first situation, patients highly valued the care provider's opinion and trusted their care provider completely. These patients feel that their care provider is always right and their advice should be followed (quote 16). Some informal caregivers explained that some patients in the passive role oblige the caregiver to assume the active role, as these patients are not always capable of making decisions themselves (quote 17).

DISCUSSION

This mixed-method study provides valuable insights into how social context, specifically subjective norms and social support, relates to older patients' perceived role in the decision-making process. Consistent with other research, patients perceive themselves as having different roles in decision-making (Degner et al., 1997; Entwistle & Watt, 2006; Matsen,

Lyons, Goodman, Biesecker, & Kaphingst, 2018). A large group seems to perceive itself as having a shared role, often advocated as the most patient-centred (Chewning et al., 2012; Elwyn et al., 2001), talking to their informal caregiver before making a decision and only involving the care provider when necessary. Many patients perceiving themselves as having an active role are open to other people's opinions, but value taking the final decision themselves. However, other studies using the Control Preference Scale show that older patients more often perceive themselves as having a passive rather than an active role (Brom et al., 2014; Cranley, Curbow, George, & Christie, 2017).

Subjective norms and patient role

Firstly, our results show a lower difference score between the patient and informal caregiver than between the patient and nurse, suggesting better alignment between the patient and informal caregiver on whether the patient or care provider should make decisions. As the interview results suggest, this could be explained by strong relationships with informal caregivers, as many are close family members (Bonsang, 2009; Doekhie, Strating, Buljac-Samardzic, van de Bovenkamp, Hester M, & Paauwe, 2018; Janse et al., 2018) who are familiar with the patient's preferences and know their medical history.

Nevertheless, our results suggest that in some cases misalignments can occur due to overprotectiveness or informal caregivers and nurses seeking reassurance from the care provider behind the patient's back, consistent with past studies on the patient's role in decision-making (Doekhie et al., 2018; Gallant, Spitze, & Prohaska, 2007). These types of misalignment are somewhat similar to misalignments found during medical consultations (Laidsaar-Powell et al., 2013), when patients expect the informal caregiver to be indirectly involved (e.g. asking questions), while informal caregivers want to be directly involved (Laidsaar-Powell et al., 2013).

Secondly, our study suggests that the more a patient thinks that their informal caregiver or nurse expects them to leave decision-making to the care provider, the more the patient perceives themselves as having a passive role in the process. This finding is consistent with Brabers and colleagues (2016), showing that a higher subjective norm score relates to a patient preferring to be less involved in the decision-making process. However, our study also suggests that patients with a higher subjective norm score are also more likely to perceive themselves as having a shared role in decision-making. This could be explained by the fact that even if patients agree with their informal caregiver or the nurse that they will not take an active role in a decision, they still value their care provider informing them and discussing treatment options with them (Chewning et al., 2012; Cranley et al., 2017; Flynn et al., 2006).

Social support and patient role

The results of this study also indicate that the more social support a patient perceives themselves as having, the more the patient will perceive themselves as having a shared role in the decision-making process. Hobbs et al. (Hobbs et al., 2015) found a similar result, suggesting that patients who perceive themselves as having a shared role value the support of any individual in their network. However, that study also showed that patients do not have a strong preference regarding with whom they want to share this role, which is not in line with our study. In line with other research, we suggest that social networks can consist of multiple circles (Agneessens, Waege, & Lievens, 2006; Kennedy, Vassilev, James, & Rogers, 2015; Rogers et al., 2016; Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014), with patients particularly valuing the emotional and instrumental support of individuals in their closest circle (i.e. informal caregivers) and want to share the decision-making with them. For everyday matters, some patients also rely on the support of the other circles: their next-of-kin, neighbours and social groups.

Notably, although most patients value the support they are given, it can be overdone, leading some patients to desire more distance and less interference. Although social network members often have a positive influence on a patient's self-management, family members could also prevent a patient from taking over too much (Doekhie et al., 2018; Gallant et al., 2007).

Limitations

Firstly, because of the cross-sectional design, we cannot draw conclusions on causality between subjective norms, social support and patient perceived roles in the decision-making process. Secondly, with regard to the survey, patients were nested in with informal caregivers and nurses. We realise that multilevel analysis is commonly performed with nested data, but we were unable to do this due to the limited sample size. However, we were able to collect data from patient-informal caregiver and patient-nurse dyads, providing new insight into the social context of specific relationships.

Thirdly, invitations to participate were sent to patients by the home care organisation and the final survey sample included only those patients who had consented and agreed to share the contact details of their caregivers. Thus, the samples of informal caregivers and nurses were not random. It is known that patient's roles may vary by ethnicity and specific diseases (e.g. cancer) (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2009) for example and our population is limited in this regard, which calls for careful consideration of the generalisability of the results. However, our survey respondents were fairly representative of the Dutch population. As 18 nurses filled in questionnaires for two or three patients, it is possible that they may have unconsciously compared their patients which might have affected their scoring. However, our mixed-method approach still provides insights into the relationship of social context to perceived patient roles. As social networks are dynamic and
the type of care needed by a patient changes over time (Doekhie et al., 2017; Vassilev et al., 2014), further research should focus on how social context could change perceived and actual patients' roles in the decision-making process.

Finally, because of our patient group of elderly patients with different chronic conditions, our study does not focus on a specific type of decision or a specific decision-making process in relation to one type of health care provider. We realise that the perceived patient role may vary depending on a specific type of decision or in relation to a specific health care provider. Therefore, although our study provides initial insight into the relationship between social context and perceived patients' roles, more research is needed about specific types of decision-making.

Practice implications

This research discusses the relationship of social context to the older patients' perceived role in decision-making. Patients could be influenced by their perception of the role expectations that others, such as their informal caregivers and nurses, have. When role expectations are not explicit, misalignments can occur. We therefore advocate creating explicit awareness of implicit expectations. Patients, informal caregivers and nurses should be encouraged to discuss their mutual role expectations. In some cases, this conversation could form an integral part of a medical appointment. As many older patients receive care and support from a large network of formal and informal care providers (Doekhie et al., 2017; LaDonna et al., 2016; Rogers et al., 2016; Weenink, van Lieshout, Jung, & Wensing, 2011), it is also important to include other relevant actors. For that reason, we recommend taking a customised approach, in which the required resources, actors involved and responsibility for organising and facilitating discussions may vary for each patient.

Secondly, our study underlines the importance of support from social networks for the patient's role. Care providers, researchers and policy makers should therefore not focus solely on (strengthening) support by informal care providers and the most involved formal care providers but take into account the patient's entire support network (Rogers et al., 2016). In line with Keating and Dosman (2009), who identify four types of support networks (i.e. family-based, friend-based, diverse mix of kin and non-kin, and limited to very few members), our study suggests a diversity of networks and the level of support. Some patients have extensive networks with a lot of support from all circles, while others have small networks or receive moderate support. It is important that researchers and policy makers take note of the patient's social network to assess the potential resources and support. Network analysis using technological tools designed to visualise patients' networks and identify resources could be helpful (Kennedy et al., 2015; Rogers et al., 2016).

CONCLUSION

The role patients perceive that they play in decision-making could be influenced by their own expectations and the expectations they believe that significant others have, such as informal caregivers and nurses, as well as the support they receive from their social network. This study therefore supports the understanding that patient involvement in decision-making is a complex concept that cannot predict patients' roles solely by demographic factors, but is influenced by and should be examined in the broader social context (Entwistle & Watt, 2006; Matsen et al., 2018).

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CHAPTER 7

Interventions to improve team effectiveness within health care: a systematic review of the past decade

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ABSTRACT

Background: A high variety of team interventions aims to improve team performance outcomes. In 2008, we conducted a systematic review to provide an overview of the scientific studies focused on these interventions. However, over the past decade, the literature on team interventions has rapidly evolved. An updated overview is therefore required, and it will focus on all possible team interventions without restrictions to a type of intervention, setting, or research design.

Objectives: To review the literature from the past decade on interventions with the goal of improving team effectiveness within healthcare organizations and identify the "evidence base" levels of the research.

Methods: Seven major databases were systematically searched for relevant articles published between 2008 and July 2018. Of the original search yield of 6025 studies, 297 studies met the inclusion criteria according to three independent authors and were subsequently included for analysis. The Grading of Recommendations, Assessment, Development, and Evaluation Scale was used to assess the level of empirical evidence.

Results: Three types of interventions were distinguished: (1) *Training*, which is sub-divided into training that is based on predefined principles (i.e. CRM: crew resource management and TeamSTEPPS: Team Strategies and Tools to Enhance Performance and Patient Safety), on a specific method (i.e. simulation), or on general team training. (2) *Tools* covers tools that structure (i.e. SBAR: Situation, Background, Assessment, and Recommendation, (de) briefing checklists, and rounds), facilitate (through communication technology), or trigger (through monitoring and feedback) teamwork. (3) *Organizational (re)design* is about (re) designing structures to stimulate team processes and team functioning. (4) A *programme* is a combination of the previous types. The majority of studies evaluated a training focused on the (acute) hospital care setting. Most of the evaluated interventions focused on improving non-technical skills and provided evidence of improvements.

Conclusion: Over the last decade, the number of studies on team interventions has increased exponentially. At the same time, research tends to focus on certain interventions, settings, and/or outcomes. Principle-based training (i.e. CRM and TeamSTEPPS) and simulation-based training seem to provide the greatest opportunities for reaching the improvement goals in team functioning.

INTRODUCTION

Teamwork is essential for providing care and is therefore prominent in healthcare organizations. A lack of teamwork is often identified as a primary point of vulnerability for quality and safety of care (Donaldson, Corrigan, & Kohn, 2000; Manser, 2009). Improving teamwork has therefore received top priority. There is a strong belief that effectiveness of healthcare teams can be improved by team interventions, as a wide range of studies have shown a positive effect of team interventions on performance outcomes (e.g., effectiveness, patient safety, efficiency) within diverse healthcare setting (e.g., Operating Theatre, Intensive Care Unit or Nursing Homes) (Hughes et al., 2016; Murphy, Curtis, & McCloughen, 2016; Neily, Mills, Young-Xu et al., 2010; Salas et al., 2008; Tan, Pena, Altree, & Maddern, 2014).

In light of the promising effects of team interventions on team performance and care delivery, many scholars and practitioners evaluated numerous interventions. A decade ago (2008), we conducted a systematic review with the aim of providing an overview of interventions to improve team effectiveness (Buljac-Samardzic, Dekker-van Doorn, Van Wijngaarden, & Van Wijk, 2010). This review showed a high variety of team interventions in terms of type of intervention (i.e., simulation training, Crew Resource Management (CRM) training, interprofessional training, general team training, practical tools, and organizational interventions), type of teams (e.g., multi-, mono-, and interdisciplinary), type of healthcare setting (e.g., hospital, elderly care, mental health, primary care), and quality of evidence (Buljac-Samardzic et al., 2010). From 2008 onward, the literature on team interventions rapidly evolved, which is evident from the number of literature reviews focusing on specific types of interventions. For example, in 2016, Hughes et al. (2016) published a meta-analysis demonstrating that team training is associated with teamwork and organizational performance and has a strong potential for improving patient outcomes and patient health. In 2016, Murphy et al. (2016) published a systematic review, which showed that simulation-based team training is an effective method to train a specific type of team (i.e., resuscitation teams) in management of crisis scenarios and has the potential to improve team performance. In 2014, O'Dea et al. (2014) showed with their meta-analysis that CRM training (a type of team intervention) has a strong effect on knowledge and behaviour in acute care settings (as a specific health care setting). In addition to the aforementioned reviews, a dozen additional literature reviews that focus on the relationship between (a specific type of) team interventions and team performance could be mentioned (Boet, Sylvain et al., 2014; Carne, Kennedy, & Gray, 2012; Doumouras, Keshet, Nathens, Ahmed, & Hicks, 2012; Fung et al., 2015; Maynard, Marshall, & Dean, 2012; McCulloch, Rathbone, & Catchpole, 2011; Russ et al., 2013; Sacks et al., 2015; Tan et al., 2014; Verbeek-van Noord et al., 2014; Weaver et al., 2010). In sum, the extensive empirical evidence shows that team performance can be improved through diverse team interventions.

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However, each of the previously mentioned literature reviews had a narrow scope, only partly answering the much broader question of how to improve team effectiveness within healthcare organizations. Some of these reviews focus on a specific team intervention, while others on a specific area of health care. For example, Tan et al. (2014) presented an overview on team simulation in the operating theatre and O'Dea et al. (2014) focused on CRM intervention in acute care. Other reviews only include studies with a certain design. For instance, Fung et al. (2015) included only randomized controlled trials, quasi-randomized controlled trials, controlled before-after studies or interrupted time series. Since the publication of our systematic review in 2010 (Buljac-Samardzic et al., 2010), there has been no updated overview of the wide range of team interventions without restrictions regarding type of team intervention, healthcare setting, type of team, or research design. Based on the number and variety of literature reviews (and related outcomes) has progressed quickly, but at the same time is quite scattered. An updated systematic review covering the past decade is therefore relevant.

The purpose of this study is to answer two research questions: (1) What types of interventions to improve team effectiveness (or related outcomes) in health care have been researched empirically, for which setting, and for which outcomes (in the last decade)? (2) To what extent are these findings evidence based?

METHODS

Search strategy

The search strategy was developed with the assistance of a research librarian from a medical library who specializes in designing systematic reviews. The search combined keywords from 4 areas: (1) *team* (e.g., team, teamwork); (2) *health care* (e.g., health care, nurse, medical, doctor, paramedic); (3) *interventions* (e.g., programme, intervention, training, tool, checklist, teambuilding); (4) *improving team functioning* (e.g., outcome, performance, function) OR a specific *performance outcome* (e.g., communication, competence, skill, efficiency, productivity, effectiveness, innovation, satisfaction, well-being, knowledge, attitude). This is similar to the search terms in the initial systematic review (Buljac-Samardzic et al., 2010). The search was conducted in the following databases: EMBASE, Medline Ovid, Web of science, Cochrane Library, PsycINFO, Cinahl Ebsco, and Google scholar. The searches were restricted to articles published in English in peer-reviewed journals between 2008 and July 2018. This resulted in 5,763 articles. In addition, 262 articles were identified through the systematic reviews published in the last decade (Boet, Sylvain et al., 2014; Borchard, Schwappach, Barbir, & Bezzola, 2012; Carne et al., 2012; Cheng et al., 2014; Gunningham, Ward, De Brún, & McAuliffe, 2018; Doumouras et al., 2012; Fung et al., 2015; Gordon & Findley,

2011; Hughes et al., 2016; Maynard et al., 2012; McCulloch et al., 2011; McEwan, Ruissen, Eys, Zumbo, & Beauchamp, 2017; Murphy et al., 2016; O'Dea et al., 2014; Reeves, Perrier, Goldman, Freeth, & Zwarenstein, 2013; Robertson, Dias, Yule, & Smink, 2017; Russ et al., 2013; Sacks et al., 2015; Shields & Flin, 2013; Tan et al., 2014; Verbeek-van Noord et al., 2014; Weaver, Dy, & Rosen, 2014; Weaver et al., 2010). In total, 6,025 articles were screened.

Inclusion and exclusion criteria

This systematic review aims to capture the full spectrum of studies that *empirically* demonstrate how *healthcare* organizations could *improve* team effectiveness. Therefore, the following studies were excluded:

- 1. Studies outside the healthcare setting were excluded. Dental care was excluded. We did not restrict the review to any other healthcare setting.
- 2. Studies without (unique) empirical data were excluded, such as literature reviews and editorial letters. Studies were included regardless of their study design as long as empirical data was presented. Book chapters were excluded, as they are not published in peer-reviewed journals.
- 3. Studies were excluded that present empirical data but without an outcome measure related to team functioning and team effectiveness. For example, a study that evaluates a team training without showing its effect on team functioning (or care provision) was excluded because it does not provide evidence how this team training affects team functioning.
- 4. Studies were excluded that did not include a team intervention or that included an intervention that did not primarily focus on improving team performance, which is likely to enhance team effectiveness (or other related outcomes). An example of an excluded study is a training that aims to improve technical skills such as reanimations skills within a team and sequentially improves communication (without aiming to improve communication). It is not realistic that healthcare organizations will implement this training in order to improve team communication. Interventions in order to improve collaboration between teams from different organizations were also eliminated.
- 5. Studies with students as the main target group. An example of an excluded study is a curriculum on teamwork for medical students as a part of the medical training, which has an effect on collaboration. This is outside the scope of our review, which focuses how healthcare *organizations* are able to improve team effectiveness.

In addition, how teams were defined was not a selection criterion. Given the variety of teams in the healthcare field, we found it acceptable if studies claim that the setting consists of healthcare teams.

Selection process

Figure 7.1 summarizes the search and screening process according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format. A four-stage process was followed to select potential articles. We started with 6,025 articles. First, each title and abstract was subjected to elimination based on the aforementioned inclusion and exclusion criteria. Two reviewers reviewed the title/abstracts independently. Disagreement between the reviewers was settled by a third reviewer. In case of doubt, it was referred to the next stage. The first stage reduced the number of hits to 639. Second, the full text articles were assessed for eligibility according to the same set of elimination criteria. After the full texts were read by two reviewers, 343 articles were excluded. In total, 297 articles were included in this review. Fourth, the included articles were summarized in table 7.1. Each article is described using the following structure:

- Type of intervention.
- Setting: setting where the intervention is introduced is described in accordance with the article, without further categorization.
- Outcomes: the effect of the intervention.
- Quality of evidence: the level of empirical evidence is based in the Grading of Recommendations Assessment Development, and Evaluation scale (GRADE). GRADE distinguishes four levels of quality of evidence;
 - A. High: future research is highly unlikely to change the confidence in the estimated effect of the intervention.
 - B. Moderate: future research us likely to have an important impact on the confidence in the estimated effect of the intervention and may change it.
 - C. Low: future research is very likely to have an important impact on the confidence in the estimated effect of the intervention and is likely to change it.
 - D. Very low: any estimated effect of the intervention is very uncertain.



Figure 7.1. Prisma flowchart

Studies can also be upgraded or downgraded based on additional criteria. For example, a study is downgraded by one category in the event there are important inconsistencies. Detailed information is provided in figure 7.2.

GRADE	Example of study designs		
A high quality of evidence	multicentre RCT, large high-quality multi-centre trial, high-quality pre- and post-surveys		
B moderate quality of evidence	one-centre RCT, RCT with severe limitations, and pre-and post-surveys		
C low quality of evidence	high-quality qualitative studies, quasi-experimental designs and pre-and post-surveys with limitations		
D very low quality of evidence	low- quality qualitative studies and pre- and post-surveys with severe limitations		
Decrease grade if:			
Decrease grade if:			
Serious (- 1) or very s Important inconsistency Some (- 1) or major (Imprecise or sparse da High probability of repo	erious (– 2) limitation to study quality y (– 1) – 2) uncertainty about directness ta (– 1) rting bias (– 1)		
 Serious (- 1) or very s Important inconsistency Some (- 1) or major (Imprecise or sparse da High probability of report 	erious (– 2) limitation to study quality y (– 1) – 2) uncertainty about directness ta (– 1) rting bias (– 1)		

Figure 7.2. GRADE

Organization of results

The categorization of our final set of 297 articles is the result of three iterations. First, 50 summarized articles were categorized using the initial categorization: team training (subcategories: CRM based training, simulation training, interprofessional training, and team training); tools; and organizational intervention (Buljac-Samardzic et al., 2010). Based on this first iteration, the main three categories (i.e., training, tools, and organizational interventions) remained unchanged but the subcategorization was further developed. Training, related to the subcategory "CRM based training", "TeamSTEPPS" was added as a subcategory. The other subcategories (i.e., simulation training, interprofessional training, and team training) remained the same. Tools, the first draft of subcategories, entailed SBAR, checklists, (de)briefing, and task tools. Two subcategories of organizational intervention (i.e., programme and (re)design) were created, which was also in line with the content of this category in the original literature review. Second, 50 additional articles were categorized to test and refine the subcategories. Based on this second iteration, the subcategories were clustered, restructured and renamed, but the initial three main categorizations remained unaffected. The five subcategories of training were clustered into principle-based training, method-based training, and general team training. The tools subcategories were clustered into structuring, facilitating, and triggering tools, which also required two new subcategories: rounds and technology.

Third, the remaining 197 articles were categorized to test the refined categorization. In addition, the latter categorization was peer reviewed. The third iteration resulted in three alterations. First, we created two main categories based on the two subcategories "organizational (re)design" and "programme" (of the third main categorization). Consequently, we rephrased "programme-based training" into "principle-based training". Second, the subcategories "educational intervention" and "general team training" were merged into "general team training". Consequently, we rephrased "simulation training" into "simulation-based training". Third, we repositioned the subcategories "(de)briefing" and "counds" as structuring tools instead of facilitating tools. Consequently, we merged the subcategories "(de)briefing" and "checklists" into "(de)briefing checklists". Thereby, the subcategory "technology" became redundant.

RESULTS

Four main categories are distinguished: training, tools, organizational (re)design, and programme. The first category, training, is divided in training that is based on specific principles and a combination of methods (i.e., CRM and Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS)), a specific training method (i.e., training with simulation as a core element), or general team training, which refers to broad team training in which a clear underlying principle or specific method is not specified. The second category, tools, are instruments that are introduced to improve teamwork by structuring (i.e., SBAR (Situation, Background, Assessment, and Recommendation), (de) briefing checklists, and rounds), facilitating (through communication technology), or triggering (through monitoring and feedback) team interaction. Structuring tools partly standardize the process of team interaction. Facilitating tools provide better opportunities for team interaction. Triggering tools provide information to incentivize team interaction. The third category, organizational (re)design, refers to (re)designing structures (through implementing pathways, redesigning schedules, introducing or redesigning roles and responsibilities) that will lead to improved team processes and functioning. The fourth category, a **programme**, refers to a combination of the previous types of interventions (i.e., training, tools, and/or redesign). Table 7.2 presents the (sub) categorization, number of studies, and a short description of each (sub) category.

Principle-bas	Principle-based Training: CRM- based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE			
Allan et al. 2010	A simulation-based in situ CRM training: game play, didactics, video review, hands-on high- fidelity simulation-based training and video-based debriefing	Paediatric cardiac intensive care	Improvement in participants' perceived ability to function as a code team member and confidence in a code, likeliness to raise concerns about inappropriate management to the code leader	С			
Ballangrud et al. 2014	Simulation-based CRM team training: introductory theory inputs on safe team performance based on CRM and a team training in a simulation laboratory	Intensive care	Training increases awareness of clinical practice and acknowledges the importance of structured work in teams	D			
Bank et al. 2014	Needs-based paediatric CRM simulation training with post activity follow-up: plenary educational session, simulation and debriefing	Paediatric emergency medicine residents (postgraduate year 1–5)	Improvement in the ability to be an effective team leader in general, delegating tasks appropriately, and ability to ensure closed loop communication, and identification of CRM errors	С			
Budin et al. 2014	CRM training: train-the-trainer program and CRM training including videos, lecture, and role-playing	Perinatal care	Improvement in nurse and physician perceptions of teamwork and safety climate	С			
Carbo et al. 2011	CRM-based training focusing on appropriate assertiveness, effective briefings, call-back and verification, situational awareness, and shared mental models	Inpatient internal medicine	Improvement in the percentage of correct answers on a question related to key teamwork principles, reporting "would feel comfortable telling a senior clinician his/her plan was unsafe'	С			
Catchpole et al. 2010	Aviation-style team training: classroom training of interactive modules including lectures and discussions, and coaching in theatre	Surgery	More time-outs, briefings, and debriefings	В			
Clay- Williams et al. 2013	CRM-based classroom training, CRM simulation training or classroom training followed by simulation training	Doctors, nurses and midwives	Improvement in knowledge, self-assessed teamwork behaviour and independently observed teamwork behaviour when classroom-only trained group was compared with control, these changes were not found in the group that received classroom followed by simulation training	A			

Table 7.1 Summary of results

Principle-bas	Principle-based Training: CRM- based training					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Cooper et al. 2008	Simulation-based anaesthesia CRM training	Anaesthesiology	No difference between the trained and untrained cohorts	С		
France et al. 2008	CRM training: CRM introductory training course (i.e. lectures, case studies, and role- playing) and perioperative CRM training (i.e. e-learning models and toolkit consisting of CRM process checklist, briefing scripts, communication whiteboard, implementation training)	Surgery	Shows potential to improve team behaviour and performance	D		
Gardner et al. 2008	Simulation-based CRM training with debriefing	Obstetrics department	Reduction in annual obstetrical malpractice premiums; improvement in teamwork and communication in managing a critical obstetric event in the interval	С		
Gore et al. 2010	CRM training: educational seminar (i.e. lectures and role-play exercises), development and expansion of time-out briefing, educational video on briefing, posters on content briefing	Operating room	Improvement in teamwork, error reporting, and safety climate	С		
Haerkens et al. 2017	CRM training: CRM awareness training (i.e. lectures and multiple interactive sessions using case studies and video footage), implementation of tools	Emergency department	Improvement in teamwork climate, safety climate and stress recognition. Increase in patient length of stay	В		
Haller et al. 2008	CRM training: video, discussion, (interactive) lectures, workshops, play roles, interactive course	Obstetrical setting in hospital	Improvement in knowledge of teamwork, shared decision making, team and safety climate, stress recognition	В		
Hefner et al. 2017	CRM training: day-long retreats, during which participants underwent developed and tailored CRM safety tools and participated in role-playing, development of system-wide internal monitoring processes	Medical centre consisting of multiple hospitals and two campuses	Improvement in (1) organizational learning and continuous improvement, (2) overall perceptions of patient safety, (3) feedback and communication about errors and (4) communication openness.	В		
Hicks et al. 2012	Crisis Resources for Emergency Workers (CREW): a simulation- based CRM curriculum: precourse learning and a full-day simulation-based exercise with debriefing	Emergency department	Believe that CREW could reduce errors and improve patient safety; no improvement towards team-based attitudes	С		

Principle-ba	Principle-based Training: CRM- based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE			
Hughes et al. 2014	CRM adapted to Trauma Resuscitation with new cultural and process expectation: CRM course of 15 sessions	Trauma resuscitation	Improvement in accuracy of field to medical command information, accuracy of emergency department medical command information to the resuscitation area, team leader identity, communication of plan, role assignment, likeliness to speak up when patient safety was a concern	В			
de Korne et al. 2014	Team Resource Management (TRM) program (based on CRM concepts): safety audits of processes and (team) activities, interactive classroom training sessions by aviation experts, a flight simulator session, and video recording of team activities with subsequent feedback	Eye hospital	Observations suggests increase safety awareness and safety- related patterns of behaviour between professions, including communication	D			
Kuy & Romero 2017	CRM training: didactics, group discussions, and simulation training	Surgical service staff at a VA Hospital	At T1 participants reported improvement in all 27 areas assessed. At T2 his improvement was sustained in 85% of the areas studied. Areas with largest improvement: briefing, collaboration, nursing input, and patient safety. Areas with regression: speaking up, expressing disagreement, level of staffing, and discussing errors	С			
LaPoint et al. 2012	CRM training: core skills workshops	Perioperative staff	Improvement in supervisor expectations, communication openness, teamwork within units, non-punitive response to error, hospital management support for safety, hand- offs. No significant improvement in organizational learning, feedback communication about errors, teamwork across hospital units, number of events	С			
Mahramus et al. 2016	Teamwork training based on CRM and TeamSTEPPS: simulations, debriefing, teamwork education	Hospital	Improvement in perceptions of teamwork behaviours	С			

 Table 7.1 Summary of results (continued)

Principle-ba	Principle-based Training: CRM- based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE			
McCulloch et al. 2009	Classroom non-technical skills training based on CRM: mixed didactic and interactive Teaching (e.g. role-play), follow- up feedback by trainers	Operating room	Improved technical and non-technical performance: improvement in attitudes to safety, team non-technical performance and technical error rates	С			
Mehta et al. 2013	Multidisciplinary simulation course: CRM teaching, simulation with debriefing, closing session with feedback	Operating room	Improvement in clinical knowledge, teamwork, leadership and non-technical skills, as well as the mutual understanding and respect between related medical and non-medical team members	D			
Morgan et al. 2015a	CRM-based training and improving working processes through implementing morning briefing and WHO Surgical Safety Checklist	Operating room conducting elective orthopaedic surgery	Improvement in non-technical skills and WHO compliance; no significant improvement in clinical outcomes	С			
Morgan et al. 2015b	Teamwork training course CRM-based interactive classroom teaching and on the job coaching	Operating rooms	Improvement in non-technical skills, but also with a rise in operative glitches	В			
Muller et al. 2009	CRM training (i.e. psychological teaching including theoretical exercises and simulator scenarios and video-assisted debriefing) versus classic simulator training (MED)	Hospital	Improvement in clinical and non-technical performance after both training, but no difference between training	С			
Parsons et al. 2018	Simulation-based CRM training: didactic presentation, series of simulation scenarios and structured debriefs	Emergency medicine	No significant improvement in leadership, problem solving, communication, situational awareness, teamwork, resource utilization and overall CRM skills	D			
Phipps et al. 2012	CRM- based training: didactic sessions, simulation and debriefing	Labour and delivery	Improvement in patient outcomes (adverse outcomes), perceptions of patient safety including the dimensions of teamwork and communication	В			
Ricci et al. 2012	CRM training: Training (i.e. didactics, case-study discussions, team-building exercises, simulated operating room brief and debrief sessions) and CRM techniques (e.g. pre-operative checklist and brief, post-operative debrief, read and initial files. feedback tools)	Perioperative personnel	Wrong site surgeries and retained foreign bodies decreased but increased after 14 months without additional training.	В			

Authors	Intervention	Setting	Outcome(s)	CRADE
(year)	Intervention	Setting	Outcome(s)	GRADE
Robertson et al. 2009	Obstetric Crisis Team Training: online module, training session (standardized, simulated crisis scenarios with simulator mannequin), and debriefings	Multidisciplinary Obstetric Providers in hospital	Improvement in attitude; perception of individual and team performance, and overall team performance	С
Savage et al. 2017	CRM safety program: CRM training (i.e. didactic seminars, role-playing), systematic risk assessments, and improving work practices (i.e. checklists, huddles or structured communication and meeting tools)	Paediatric surgery	Improvement in non-technical skills, the use of safety tools, adherence to guidelines, safety culture (i.e. teamwork across and within units, supervisors' expectations and actions, non- punitive response to adverse events, perceptions of overall patient safety); unplanned readmissions following appendectomy declined	A
Sax et al. 2009	CRM training: video, team building exercises, open forum, and development and implementation of perioperative checklist	Hospitals	Increased self-initiated error reports and perceived self- empowerment	В
Shea-Lewis et al. 2009	CRM-based training: real life examples, feedback, SBAR, team meetings, briefing, and debriefing	Obstetric department	Improvement in patient outcome, patient satisfaction, employee satisfaction	С
Schwartz et al. 2017	Clinical Team Training (CTT) based on CRM principles: training (e.g. simulation) and implementation of improvement projects (e.g. briefing, huddles, checklists)	Veterans Health Administration facilities	Improvement in communication, teamwork and situational awareness for patient safety. Also decreased between T1 and T2 detected.	В
Sculli et al. 2013	Nursing CRM: interactive didactic training curriculum, features high fidelity simulation, ongoing consultation, improvement project, refreshment	Nursing units	Improvement unit climate, teamwork, medication errors, HAPU, glucose control, FTR events, and care processes	С
Steinemann et al. 2011	Crisis Team Training-based in situ team training: web based didactic, simulations, and debriefing	Emergency department	Improvement in teamwork ratings, clinical task speed and completion rates, teamwork scores, objective parameters of speed and completeness of resuscitation	В

Table 7	.1	Summary	of	results	(continued)
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Principle-ba	Principle-based Training: CRM- based training					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Stevens et al. 2012	CRM-based educational program based on high realism acute crisis simulation scenarios and interactive workshop	Cardiac surgery	Survey: improvement in the concept of working as a team. Interview: improvement in personal behaviours and patient care, including speaking up more readily and communicating more clearly	D		
Suva et al. 2012	CRM training: introductory course, interactive workshops, lecture, role-play	Operating room	Improvement in learning, knowledge regarding teamwork, safety climate, and stress recognition; improvement varies with participant specialty	С		
Tschannen et al. 2015	Nursing CRM training: educational sessions, podcasts, simulation and debriefing	General medicine telemetry unit	No significant improvement in communication openness and environmental values; RNs reported an increase in both synchronous communication and asynchronous communication with physicians whereas physicians noted a reduction in time spent in asynchronous communication	D		
West et al. 2012	Nursing CRM training: didactic session, simulation, implementation of a CRM technique: sterile cockpit rule	Veterans Affairs hospital on nursing units	Improvement in efficiency (e.g. quicker follow-up on abnormal vital signs and blood glucose levels, rapid assessment of patients with changes in condition, and faster intervention when the condition was deteriorating) and perceived teamwork, communication, patient safety	С		
Ziesmann et al. 2013	STARTT (Standardized Trauma and Resuscitation Team Training): lectures (on CRM), discussion based on CRM principles, simulations and debriefing	Trauma teams	Improvement in overall CRM domains, teamwork, and safety climate	D		

Program-bas	sed Training: TeamSTEPPS			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Armour Forse et al. 2011	TeamSTEPPS	Operating room	Improvement in communications, leadership first case starts, Surgical Quality Improvement Program measures, surgical morbidity and mortality, culture; not all improvement were sustained. No significant effect on PACU communication and teamwork	В
Bridges et al. 2014	Educational intervention: adapted TeamSTEPPS curriculum, discussion, practicing standardized communication tools	Hospital Intermediate Care Unit serving adult medical cardiac patients	Improvement in awareness of teamwork and backup	С
Brodsky et al. 2013	Multidisciplinary, small group, interactive workshop based on TeamSTEPPS	Neonatal intensive care	Improvement in the overall teamwork, communication, situation awareness, support, satisfaction, job fulfilment, respect	В
Bui et al. 2018	Video and live observation of TeamSTEPPS skills implementation during surgical briefs and debriefs	Operating Rooms	Low compliance with TeamSTEPPS skills; compliance was under video observation than under live observation	D
Capella et al. 2010	TeamSTEPPS (e.g. didactic session, simulation, 5 tools: briefing, STEP (situation monitoring tool), CUS (mutual support tool), call outs, and check backs)	Level I Trauma Centre	Improvement in leadership situation monitoring, mutual support, communication, and overall teamwork; decreasing the times from arrival to the CT scanner, endotracheal intubation and the operating room	В
Castner et al. 2012	TeamSTEPPS	Hospital inpatient bedside RNs	Improved perceptions of leadership	С
Deering et al. 2011	TeamSTEPPS	Combat support hospital	Decreases in the rates of communication-related errors, medication and transfusion errors, and needles tick incidents, the rate of incidents coded communication as the primary teamwork skill that could have potentially prevented the event	С
Figueroa et al. 2013	TeamSTEPPS-based simulation training: lecture (on TeamSTEPPS principles), simulation, checklist, and debriefing	Paediatric cardiovascular intensive care	Improving confidence, skills in the role of team leaders, and TeamSTEPPS concepts	В

Program-bas	ed Training: TeamSTEPPS			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Gaston et al. 2016	Customized TeamSTEPPS training (of 2 instead of 6 hours)	Oncology acute patient care	Improvement in staff perception of teamwork and communication	В
Gupta et al. 2015	A selection of TeamSTEPPS tools	Academic interventional ultrasound service	Improvement in teamwork climate, safety climate, and teamwork	С
Harvey et al. 2014	In situ simulation-based training (SBT) versus case study review, both incorporating TeamSTEPPS training	Medical-surgical PCUs	Improvement in knowledge and teamwork skills in both groups; SBT group showed greater improvement in all areas except knowledge	С
Jones et al. 2013	TeamSTEPPS (e.g. TeamSTEPPS tools, fundamentals course)	Hospitals	Improvement in safety culture	А
Jones et al. 2013	TeamSTEPPS (e.g. essentials course)	Emergency Department	Improvement of staff perception related to a culture of safety (e.g. management support for patient safety, feedback and communications about error, communication openness)	В
Lee et al. 2017	After TeamSTEPPS, implementation of reinforcement activities regarding leadership and communication (i.e. lectures, self- paced learning program, 1 page summary, and grand rounds on TeamSTEPPS principles)	Orthopaedic surgery	Nursing staff: improvement in leadership and communication behaviours. Surgical staff: improvement in leadership behaviours. Anaesthesia staff: no improvement in any teamwork behaviours	С
Lisbon et al. 2016	TeamSTEPPS: brief, huddle, DESC (constructive approach for managing and resolving Conflict) and CUS script	Academic emergency department	Improvement in knowledge and improved communication attitudes; adoption of a specific behaviour, the huddle, also was observed	В
Mahoney et al. 2012	TeamSTEPPS (variation of tools: flyers, simulations, games, and sustainment tools such as luncheon debriefing, awards)	Psychiatric hospital	Improvement in team foundation, functioning, performance, skills, climate, and atmosphere	В
Mayer et al. 2011	TeamSTEPPS (e.g. fundamental curriculum)	Paediatric and surgical intensive care	Improvement in experienced teamwork, team performance, communication openness and clinical outcomes (e.g. average time for placing patients on extracorporeal membrane oxygenation, average duration of adult surgery rapid response team events	В

Program-bas	sed training: teamSTEPPS			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Rice et al. 2016	Modified simulation-based TeamSTEPPS training	Intensive care	Improvement in teamwork attitudes, perceptions, and performance	D
Riley et al. 2011	TeamSTEPPS didactic training (e.g. webinar, video of simulated scenario's) versus full TeamSTEPPS training (e.g. series of in-situ simulation training exercises including (de)briefing, rapid-cycle follow-through with process improvements, and repetition	Hospitals	Improvement in perinatal morbidity between the pre- and post-intervention for hospital with simulation program. No significant changes in safety culture	В
Sawyer et al. 2013	TeamSTEPPS training (e.g. fundamental course) with medical simulation	Neonatal intensive care	Improvement in teamwork skills in team structure, leadership, situation monitoring, mutual support, and communication, the odds of a nurse challenging an incorrect medication dose, and detection and correction of inadequate chest compressions	С
Sonesh et al. 2015	Adapted TeamSTEPPS (lecture based interactive program)	Obstetrical setting	Improvement in knowledge of communication strategies, decision accuracy, and length of babies' hospital length of stay. Knowledge of other team competencies or self-reported teamwork did not significantly improve	С
Spiva et al. 2014	Training curriculum based on TeamSTEPPS (e.g. didactic lecture, patient video vignettes, debriefing)	Hospital	Improvement on fall reduction and teamwork	В
Stead et al. 2009	TeamSTEPPS (e.g. redesign meetings, SBAR, coaching)	Mental health facility	Substantial impact on patient safety culture (i.e. frequency of event reporting, and curriculum learning), teamwork, communication, KSA score, rates of seclusion. Issues around staffing, teamwork across hospital units, and hospital management support remained unchanged	D

Program-bas	Program-based Training: TeamSTEPPS					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Thomas et al. 2012	TeamSTEPPS (e.g. master trainer course, fundamentals course, essentials course)	Hospital	Improvement in feedback and communication about error, frequency of events reported, hospital handoff and transitions, staffing, and teamwork across the units	С		
Treadwell et al. 2015	TeamSTEPPS (e.g. huddle, debrief, SBAR, briefing checklist)	Medical home	Improved perception of team collaboration	С		
Vertino 2014	TeamSTEPPS (e.g. formal presentation, discussion, role-play exercises embodying clinical scenarios)	Inpatient (VHA) hospital unit	Positive change in staff attitudes towards team structure, leadership, situation monitoring, mutual support, and communication	D		
Weaver et al. 2010	TeamSTEPPS (e.g. didactic session, interactive role-playing, multiple tools)	Operating Rooms	Improvement in quality and quantity of briefings and the use of quality teamwork behaviours during cases	В		
Wong et al. 2016	Interprofessional education course: adapted TeamSTEPPS curriculum, simulation scenarios, and structured debriefing, and wrap-up session	Emergency department	Improvement in team structure, leadership, situation monitoring, mutual support, frequency of event reporting, teamwork within hospital units, and hospital handoffs and transitions	В		

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
AbdelFattah et al. 2018	Trauma-focus simulation training: trauma simulations with video- based debriefing	Trauma surgery	Improvement in clinical management, leadership, communication, cooperation, professionalism and performance on trauma rotation	D		
Amiel et al. 2016	One-day simulation- based training with video-based debriefing	Emergency department in trauma centre	Improvement in teamwork, communication, patient handoff, and shock and haemorrhage control	С		
Arora et al. 2014	Full-hospital simulation across the entire patient pathway (with integration of teams in prehospital, through-hospital, and posthospital care)	Hospital	Improvement in decision- making, situational awareness, trauma care, and knowledge of hospital environment. Behavioural skills, such as teamwork and communication, did not show significant improvement	С		

Method-base	ed Training: Simulation-based train	ung		
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Arora et al. 2015	Simulation-based training for improving residents' management of postoperative complications: ward-based scenario's and debriefing intervention	Surgery	Clinically, improvement in residents' ability to recognize/ respond to falling saturations, check circulatory status, continuously reassess patient, and call for help. Teamwork, improvement in residents' communication, leadership, decision-making skills, and interaction with patients (empathy, organization, and verbal and nonverbal expression)	В
Artyomenko et al. 2017	Simulation training sessions for urgent conditions with debriefing	Obstetrical anaesthesiologists	Improvement in speed and invasive techniques, teamwork and effectiveness after the fifth session	С
Auerbach et al. 2014	In situ interdisciplinary paediatric trauma quality improvement simulation: simulated patient care followed by debriefing	Tertiary care paediatric emergency department	Improvement in overall performance, teamwork, and intubation subcomponents	С
Bender et al. 2014	Simulation-enhanced booster session (after Neonatal Resuscitation Program): orientations session, simulation, and debriefing	Paediatric and Family Practice	The intervention group demonstrated better procedural skills and teamwork behaviours. The NICU program demonstrated better teamwork behaviours compared with non- NICU program	В
Bittencourt et al. 2015	In-centre simulation-based training (simulation and debriefing) and in situ simulation (simulation and debriefing): comparison of actual paediatric emergencies, in-centre simulations, and in situ simulations	Paediatric level one trauma centre	Mean total TEAM scores were similar among the 3 settings. Simulation-based training improved communication, team interaction, shared mental models, clarifying roles and responsibilities, and task management	В
Bruppacher et al. 2010	Training session with either high-fidelity simulation-based training (i.e. orientation session, simulation, and debriefing) or an interactive seminar (i.e. audio- visual aids such as PowerPoint slides, handouts, and face-to- face discussion of paper-based scenarios similar to the simulation training)	Anaesthesiology for cardiopulmonary bypass	Both groups improved, the simulation group showed significantly higher improvement on situation awareness, team working, decision-making, task management, and checklist performance compared with the seminar group	В

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Bursiek et al. 2017	Interdisciplinary (high- fidelity) simulation training with debriefing	Interdisciplinary teams	Improvement in teamwork, perception of work environment and patient safety	С		
Burton et al. 2011	Simulation-based training: simulation laboratory curriculum with video-assisted debriefings	Extracorporeal membrane oxygenation emergencies	No improvement in timed responses or percent correct actions. Improvement in teamwork, knowledge, and attitudes	С		
Chung et al. 2011	Conventional simulation-based training (i.e. lecture, video's, simulations, and debriefing) versus a script-based training	Cardiopulmonary resuscitation in emergency departments	Both type of training improved leadership scores, but no improvement in performance	В		
Cooper et al. 2012	Simulation team training: formative questionnaire, team- based videoed scenarios, photo elicitation, and expert feedback sessions	Hospital nurse teams	Improvement in knowledge, confidence and competence; group debriefing session enhanced learning	С		
Ciporen et al. 2018	Crisis management simulation training: instructions, simulation, and debriefing	Neurosurgery and anaesthesiology	No significant differences between groups in situation awareness, decision-making, communication and teamwork	С		
Ellis et al. 2008	High-technology training at a simulation centre versus low-tech training in local units (with and without teamwork theory)	Midwives and obstetricians in hospitals	Improvement in rates of completion for basic tasks, time to administration of magnesium sulphate, and teamwork. Training in a simulation centre and teamwork theory had no effect	В		
Fernando et al. 2017	Interprofessional simulation training with debriefing	Primary and secondary care doctors	Improvement in knowledge, confidence and attitudes. Qualitative data indicates improvement in clinical skills, reflective practice, leadership, teamwork and communication skills	С		
Fouilloux et al. 2014	Training based on an animal simulation model	Cardiac surgery	Improvement in management of the adverse events and time spend per certain events	D		
Fransen et al. 2012	Multiprofessional simulation team training: introduction video, simulation, and debriefing	Obstetric departments	Improvement in teamwork performance and use of the predefined obstetric procedures	А		

Method-based Training: Simulation-based training							
Authors (year)	Intervention	Setting	Outcome(s)	GRADE			
Freeth et al. 2009	Simulation-based interprofessional training with video-recorded debriefing	Delivery	Improvement in knowledge and understanding of interprofessional team working, especially communication and leadership in obstetric crisis situations	С			
Frengley et al. 2011	Simulation-based training: familiarization, teamwork session (presentation, video, and discussions), skills station, simulations or case-based training	Critical care	Improvement in overall teamwork, leadership, team coordination, verbalizing situational information, clinical management; no difference between simulation-based learning and case-based learning	В			
George & Quatrara 2018	Interprofessional simulation training: introduction session, simulation, and debriefing	Surgical trauma burn intensive care unit	Improvement in perceptions of teamwork and knowledge	D			
Gettman et al. 2009	High Fidelity Operating Room Simulation: introduction, simulation, and video-based debriefing	Orology, operating room	Improvement in teamwork, communication, laparoscopic skills, and team performance	С			
Gilfoyle et al. 2017	Simulation-based training: lecture, group discussions, simulations, and debriefing	Paediatric resuscitation	Improvement in clinical performance and clinical teamwork (role responsibility, communication, situational awareness and decision-making)	В			
Gum et al. 2010	Interprofessional simulation training with video-based debriefing	Maternity emergency	Ability for collaboration in teambuilding (i.e. personal Role Awareness, interpositional knowledge, mutuality and leadership)	D			
Hamilton et al. 2012	High-fidelity simulated trauma resuscitation with video-assisted debriefing	Surgery	Improvement in team function score and the feeling of being more competent as team leaders and team members	В			
Hoang et al. 2016	Training course: classroom didactic sessions and hand-on simulation sessions	(U.S. Navy Fleet) surgery	Improvement in time to disposition and critical errors	D			
James et al. 2016	Simulation-based interprofessional team training: simulation followed by debriefing and performance feedback	Oncology	Acquired new knowledge, skills, and attitudes to enhance interprofessional collaboration	С			
Kalisch et al. 2015	Virtual simulation training with introduction session	Medical–surgical patient care unit	Improvement in overall teamwork, trust, team orientation, and backup	D			

 Table 7.1 Summary of results (continued)

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Khobrani et al. 2018	Boot camp curriculum with high- fidelity paediatric simulations with debriefing	(Paediatric) emergency medicine	Improvement in teamwork performance (leadership, cooperation, communication, assessment and situation) and basic knowledge	D		
Kilday et al. 2012	Team intervention: didactic curriculum with skill lab practice sessions, simulations, debriefing	Hospitals	Improvement in team performance, knowledge, and emergency teamwork	С		
Kirschbaum et al. 2012	Multidisciplinary team training: assessments, high fidelity simulation sessions, and debriefing	Obstetricians and anaesthesiologists	Improvement in teamwork cultural attitudes and perceptions, communication climate; decreases in autonomous cultural attitudes and perceptions	С		
Koutantji et al. 2008	Simulations with debriefing and in between an interactive workshop on briefing, check- listing methods and protocol	Surgery	Improvement in technical skills and no or negative effect on non-technical skills	D		
Kumar et al. 2018	Simulation-based Practical Obstetric Multi-Professional Training (PROMPT): interactive lectures, scenario's-based drills, debriefing	Obstetric care in hospitals	Improvement in clinical and non-technical skills highlighting principles of teamwork, communication, leadership and prioritization in an emergency situation. No significant change in clinical outcomes	В		
Larkin et al. 2010	Simulation-Based curriculum: video demonstrations, triggers, and simulated scenarios	Surgery	Improvement in empathic communication. Higher levels of stress. No significant improvement in teamwork attitudes	С		
Lavelle et al. 2018	Multi-disciplinary simulation- based training designed to address Medical Emergencies in Obstetrics: lecture, orientation session, simulation, debriefing, didactic teaching	Healthcare staff across organisations	Improvement in clinical skills and non-technical skills including teamwork, communication and leadership skills	D		

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Lavelle et al. 2017	In situ, simulation training: introduction, simulation, and debriefing	Psychiatric triage wards	Improvement in knowledge, confidence, and attitudes towards managing medical deterioration. Based on reflection: improved confidence in managing medical deterioration, better understanding of effective communication, improved self-reflection and team working, and an increased sense of responsibility for patients' physical health. Incident reporting increased by 33%	С		
Lee et al. 2012	Interdisciplinary high-fidelity simulation based team training with debriefing	Urology	Urology resident training correlated with technical performance but not with nontechnical performance; anaesthesia resident training level did correlate with nontechnical performance	D		
Lorello et al. 2016	Mental practice training (versus ATLS training) and simulation with debriefing	Trauma resuscitation	Improvement in teamwork behaviour, compared to traditional simulation-based trauma instruction	В		
Mager et al. 2012	Expanded Learning and Dedication to Elders in the Region (ELDER): simulated patient scenarios using mid- fidelity human patient simulators and debriefing	Long-term care facilities and home care agency	Encouraging communication and teamwork	С		
Maxson et al. 2011	Interdisciplinary simulation team training with high-fidelity simulation scenarios, pre- and debriefing session	Inpatient surgical ward	Improvement in collaboration between nurses and physicians and patient care decision- making process	С		
McLaughlin et al. 2011	Intensive trauma team training course (ITTTC): didactic lectures, case studies, and clinical simulations	Military health care personnel	Creates self-reported confidence	D		
Meurling et al. 2013	Simulation based team training: interactive seminars, simulation with debriefing	Intensive care	Improvement in self-efficacy. Improvement in nurse assistants' perceived quality of collaboration and communication with physician specialists, teamwork climate, safety climate (also for nurses) and working conditions	D		

Ta	ble	7.1	Summary	of	resu	lts ((continued)	
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Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Miller et al. 2012	In situ trauma simulation program: didactic session, simulation, and debriefing	Emergency department	Improvement in teamwork and communication, this effect was not sustained after the program was stopped	D		
van der Nelson et al. 2014	Multidisciplinary simulation training with team debriefing (with emphasizes on using clinical tools)	Surgery	Improvement in safety culture, teamwork climate; deterioration in perceptions of hospital management and adequacy of staffing levels	С		
Nicksa et al. 2015	Simulation of high-risk clinical scenarios followed by debriefings with real-time feedback	General surgery, vascular surgery, and cardiothoracic surgery	Improvement in communication, leadership, teamwork, and procedural ability. No significant improvement in decision- making, situation awareness, and skills	С		
Niell et al. 2015	Simulation-based training: didactic instruction, simulation, and debriefing	Radiology	Improvement in their ability to manage an anaphylactoid reaction, their ability to work in a team, and knowledge	В		
Oseni et al. 2017	Training: video-based feedback and low fidelity simulation	Research unit clinics and hospital (in low resource settings)	Improvement in clinical knowledge, confidence and quality of teamwork (leadership, teamwork and task management)	С		
Paige et al. 2009	Repetitive training using high- fidelity simulation: Module 1 targeted teamwork competencies and Module 2 included a preoperative briefing strategy	Operating room	Improvement in the effectiveness of promoting attitudinal change toward team- based competencies	С		
Paltved et al. 2017	In situ simulation: information, simulation, and debriefing	Emergency Department	Improvement in teamwork climate and safety climate	С		
Pascual et al. 2011	Human patient simulation training: introduction, simulation, and video-based debriefing	Intensive care	Improvement in leadership, teamwork, and self-confidence skills in managing medical emergencies	С		
Patterson et al. 2013a	Multidisciplinary in situ simulations with debriefing	Paediatric emergency department	Ability to identify latent safety threats, but changes in non- technical skills	С		
Patterson et al. 2013b	Simulation-based training: introduction (lectures, videotapes of simulated resuscitations and case studies), simulation, and video assisted debriefing	Paediatric emergency department	Sustained improvement in knowledge of and attitudes toward communication and teamwork behaviours	С		

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Pennington et al. 2018	Long distance, remote simulation training with Checklist for Early Recognition and Treatment of Acute Illness (CERTAIN)	Interdisciplinary teams in emergency situations	Improvement in global team performance: 'team's ability to complete tasks in a timely manner' and in the 'team leader's communication to the team'	С		
Rao et al. 2016	Simulation team tasks: presentation, live-demonstration, and simulations	Operating Room	Improvement in mean non- technical skills and concomitant increase in technical skills	D		
Reynolds et al. 2011	Multidisciplinary simulation- based team training: introduction, presentation, simulation, and debriefing	Obstetrical emergencies	Improvement in knowledge, dealing with teamwork related issues, and (technical) skills (particularly relevant for obstetric nurses and for those who witness all trained obstetrical emergencies)	C		
Roberts et al. 2014	Team communication, leadership and team behaviour training: didactic presentations, simulation, and debriefing	Emergency department (ad-hoc emergency teams)	Changed teamwork and communication behaviour	С		
Rubio- Gurung et al. 2014	In situ simulation training: briefing, simulation, and debriefing	Delivery room	Improvement in the technical skills and teamwork	В		
Sandahl et al. 2013	Simulation team training: lectures, simulation, and debriefing	Intensive care	Increased awareness of the importance of effective communication for patient safety, created a need to talk, led to reflection meetings	С		
Shoushtarian et al. 2014	Practical Obstetric Multi- professional Training (PROMPT): lectures, scenario- based simulation training	Maternity	Improvement in Safety Attitude (teamwork, safety and perception of management) and clinical measures (Apgar 1, cord lactates and average length of baby's stay in hospital)	В		
Siassakos et al. 2011	Interprofessional training program: updates on evidence- based guidelines and simple practical means of implementing them, high-fidelity simulation	Maternity unit	Positive safety culture, teamwork climate, and job satisfaction. Perceptions of high workload and insufficient staffing levels were the most prominent negative observations	D		
Siassakos et al. 2011	Multiprofessional simulation training	Maternity unit	Reduction in median diagnosis– delivery interval (as indicator of teamwork)	С		

Method-based Training: Simulation-based training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Silberman et al. 2018	High-fidelity human simulation training: briefing, simulation, and debriefing	Intensive care	Facilitates teamwork, collaboration, and self-efficacy for ICU clinical practice	D		
Stewart- Parker et al. 2017	Simulation-based S-TEAMS course: lectures, case studies, interactive teamwork exercises, simulated scenarios, debriefing	Operating room	Increase in confidence for speaking up in difficult situations, feeling the S-TEAMS had prevented participants from making errors, improved patient safety and team working	С		
Stocker et al. 2012	Multidisciplinary in situ simulation programme (SPRinT) with debriefing	Paediatric intensive care	Impact on non-technical skills (teamwork, communication, confidence) and overall practice; less impact is perceived in technical skills	C		
Sudikoff et al. 2009	High-fidelity medical simulation: didactic teaching, hands-on skills stations, case simulation, video- enhanced debriefing (with and without supplemental education)	Paediatric emergency care	Improved performance and teamwork skills; reduction in harmful actions	D		
Thomas et al. 2010	Teamwork training: information session with examples and SBAR model, video clips, role-playing, simulation, debriefing	Paediatric	Improvement in frequent teamwork behaviours, workload management and time to complete the resuscitation	В		
Weller et al. 2016	Multidisciplinary Operating Room Simulation (MORSim) intervention: simulation, debriefing, and discussion	Operating Room	Improvement in communication, culture and collaboration. But difficulties with uninterested colleagues, limited team orientation, communication hierarchies, insufficient numbers of staff exposed to MORSim and failure to prioritise time for team information sharing	D		
Willaert et al. 2010	Patient-specific virtual reality (VR) simulation	Operating Room	Improvement in sense of teamwork, communication, and patient safety; procedure time took longer in reality	С		
Yang et al. 2017	Simulation-based interprofessional education course: preparation course, simulation, benchmarking, e-learning	Medical centre	Improvement in inter- professional collaboration attitude, self-reflection, workplace transfer and practice of the learnt skills	D		

General Trai	General Training							
Authors (year)	Intervention	Setting	Outcome(s)	GRADE				
Acai et al. 2016	Educational creative professional development workshop: various interactive teambuilding games, activities rooted in the dramatic arts, creative printmaking session, debriefing sessions	Mental health and social care	Positive impact on teams with low team cohesion prior to the intervention. Helps staff to bond, communicate, get to know each other better and accept each other's mistakes	D				
Agarwal et al. 2008	McMaster Interprofessional Mentorship and Evaluation (MIME) program to increase interprofessional interactions, learn more about the roles of other health care professionals and improve work-life satisfaction through intentional conversations at mutually agreed times	Interprofessional family health teams	No significant improvement in the QWL Survey, but participant feedback from closing workshop focus groups and evaluations was positive	С				
Amaya-Arias et al. 2015	Team training: workshops, virtual modules, time-out and checklist training, and institutional actions	Operating rooms and obstetrics suites	Two or more points of improvement in the average OTAS-S scores in every phase, behaviours and sub-teams	С				
Barrett et al. 2009	Intervention on lateral violence and team building: interactive groups sessions and skill-building sessions	Acute care hospital	Improvement in group cohesion and the RN-RN interaction	С				
Bleakley et al. 2012	Complex education intervention: data-driven iterative education in human factors, establishing a local, reactive close call incident reporting system, and developing team self review (briefing and debriefing)	Operating room	Improvement in teamwork climate and reduction in stress recognition. No significant improvement in job satisfaction, perception of management, working conditions, safety climate	В				
Blegen et al. 2010	Multidisciplinary teamwork and communication training: presentations, video's, role- playing, and facilitated discussion	Inpatient medical units	Improvement in supervisor manager expectations, organizational learning, communication openness, hospital handoffs and transitions, and non-punitive response to error	В				
Brajtman et al. 2009	Interprofessional educational intervention: interactive sessions consisting of a case study, discussions and presentation	Palliative care	Improvement in leadership, cohesion, communication, coordination and conflict domains	D				

General Training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Brajtman et al. 2012	Interprofessional educational intervention: self-learning module (SLM) on end-of-life delirium and interprofessional teamwork, team objective structured clinical encounter (e.g. simulation team discussion and debriefing), and a didactic "theory burst"	Long-term care facility and hospice	Improvement in knowledge and perceptions of IP competence, but does depend on the presences of the module	D		
Brandler et al. 2014	Team-based learning sessions: preparation reading, tests, and application-oriented activities	Pathology	Able to solve complex problems and work through difficult scenarios in a team setting	D		
Chan et al. 2010	Intervention: educational workshop (e.g. case study using role-play) and structured facilitation using specially designed materials	Primary care	Improvement in patient participation, empowerment in the care process, communication and collaboration	С		
Christiansen et al. 2017	Standardized Staff Development Program: educational session (i.e. lecture) and teambuilding and resiliency session (e.g. simulation game, rounds)	Burn centre	Contributed to perceived unit cohesion and increasing satisfaction and morale	D		
Chiocchio et al. 2015	Workshops integrating project management and collaboration: active, learner-centred, practice- oriented strategies, feedback, and small group discussions	Interprofessional health care project teams	Improvement in satisfaction, perceptions of utility, self- efficacy for project-specific task work, teamwork, goal clarity, coordination, functional performance of projects	С		
Cohen et al. 2016	Allied Team Training for Parkinson (ATTP): interprofessional education training on best practices and team-based care	Targeted professionals (e.g. medicine, nursing, occupational, physical and music therapies)	Improvement in self-perceived, objective knowledge, understanding role of other disciplines, attitudes toward health care teams, and the attitudes toward value of teams	В		
Cole et al. 2017	Elective rotation of operating room management and leadership training: curriculum consisting of leadership and team training articles, crisis management text, and daily debriefings	Anaesthesiology	Improvement in teamwork, task management and situational awareness	D		
General Train	ning					
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Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Eklöf & Ahlborg Jr 2016	Dialogue training: multiple dialogue rounds using standardized flashcards, group discussions	Hospital	Improvement in participative safety (i.e. information sharing, mutual influence and sense of having a common task) and social support from managers. Qualitative data shows a positive tendency towards trust/ openness	A		
Ellis & Kell 2014	Training: theory, group exercises, presentations,	Paediatric ward	Improvement in team cohesiveness, effectivity, and patient care	D		
Ericson- Lidman & Strandberg 2013	Intervention to constructively deal with their troubled conscience related to perceptions of deficient teamwork: assist care providers in extending their understanding of the difficult situation and find solutions to the problem through participatory action research	Elderly care	Support care providers to understand, handle and take measures against deficient teamwork. Using troubled conscience as a driving force can increase the opportunities to improve quality of care	D		
Fallowfield et al. 2014	Communication skills training: workshop (e.g. presentations, exercises, discussion, role-play),	Breast cancer teams	Improvement in awareness and clarity about the trial(s) discussed during the training	С		
Fernandez et al. 2013	Computer-Based Educational Intervention: computer- based training module (e.g. presentations, clinical examples, simulation-based assessment) or a placebo training module	Emergency care (and medical students)	Improvement in teamwork and patient care	В		
Gibon et al. 2013	Patient-oriented communication skills training module (e.g. information, role- play) and team-resource oriented communication skills training module (e.g. information, role- play)	Radiotherapy	Improvement in team members' communication skills and their self-efficacy to communicate	В		
Gillespie et al. 2017	Team training program (TEAMANATOMY): one-hour DVD (i.e. individual and shared situational awareness theory, filmed simulation preoperative patient sign-in, and filmed simulation of time-out procedure)	Operating room	Improvement in non-technical skills (communication and interactions, situational awareness, team skills, leadership and management skills and decision-making). Most significant improvement observed in surgeons. Improved use of the surgical safety checklist	С		

Table 7.1	Summary	of resul	lts ((continued)	
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General Train	General Training						
Authors (year)	Intervention	Setting	Outcome(s)	GRADE			
Gillespie et al. 2017	Team training program (TEAMANATOMY): one-hour DVD (i.e. individual and shared situational awareness theory, filmed simulation preoperative patient sign-in, and filmed simulation of time-out procedure)	Operating room	Improvement in non-technical skills (communication and interactions, situational awareness, team skills, leadership and management skills and decision-making) and the use of the surgical safety checklist. No improvement in perceived teamwork. No significant increase in perceived safety climate	С			
Halverson et al. 2009	Team training: classroom curriculum, intraoperative coaching on team-related behaviours, and follow-up feedback sessions	Operating room	Improvement in perception of teamwork	С			
Howe et al. 2018	Rural Interdisciplinary Team Training Program: didactic mini- lectures, interactive case studies discussions, video presentations, role-play demonstrations and the development of an action plan	Veteran affairs primary care	Improvement in teamwork	D			
Kelm et al. 2018	Mindfulness meditation training using a meditation device and smartphone application at home (e.g. education, demonstration, and practice in using device, one- page summary)	Pulmonary and critical medicine physicians and ICU	Improvement in teamwork, task management, and overall performance Change in how participants responded to work-related stress, including stress in real- code situations.	D			
Khanna et al. 2017	Training and refresher courses on the principles of the patient centred care medical homes: participating patient-centred medical home received coaching, learning collaborative for improving teamwork, embedded care manager	Primary care	No significant difference in perceptions of teamwork	D			
Körner et al. 2017	Team coaching: identification of the expectations for team coaching (need-specific), definition of the coaching goals (task-related), development of the solution (solution-focused), maintenance of the solution (systemic)	Rehabilitation teams	Improvement in team organization, willingness to accept responsibility and knowledge integration according to staff. No significant improvement in internal participation, team leadership and cohesion	В			

General Training					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Lavoie- Tremblay et al. 2017	Transforming Care at the Bedside (TCAB) Program: learning modules combined with hands-on learning	Multihospital academic health science centre	Improvement in patient satisfaction focus, overall perceived team effectiveness, perceived team skill, perceived participation and goal agreement, perceived organizational support. No significant improvement in patient experience	C	
Lee et al. 2012	Communication and Patient Safety (CASP) training: practical exercises, video clips, small-group discussion and other learning techniques	Emergency, outpatients, maternity, and special care nursery	Changes in behaviour at individual, team and facility levels	С	
Ling et al. 2016	BASIC (Basic Assessment and Support in Intensive Care) Patient Safety Course: blended learning course with flipped classroom approach (e.g. lectures, formative assessment, interactive sessions)	Intensive care	Improvement in teamwork within hospital units and hospital management support for patient safety, but decreased in the frequency of reporting mistakes	С	
Lundén et al. 2017	Drama Workshop (warm-up activities, improvisations and Forum Theatre, reflective discussions) as a learning medium	Radiographers and registered nurses specialized in areas such as radiography, operating room and anaesthesia	Enables participants to understand each other's priorities better and find the best way to co-operate	D	
Mager et al. 2014	Teambuilding activities: interactive activities, discussions, case studies, readings, and/or games to promote the application of teamwork skills	Long-term and home care	Quantitatively: no statistical improvement; qualitatively: better understanding of other provider roles	С	
Magrane et al. 2010	Learning in Teams model: interactive workshops, daily program team meetings, conference calls, weekly online correspondence, and colloquium	Academic health centres	Improvement in team skills (clarifying team charge, exploring team purpose, and evaluating team process) and institutional team performance	С	
Nancarrow et al. 2015	Interdisciplinary Management Tool (IMT): structured reflection through reflective exercises, facilitated sessions, evaluation conference	Community based rehabilitation or community rehabilitation services providing transitional care for older people	Empowers to understand and value their own, and others' roles and responsibilities within the team; identify barriers to effective teamwork, and develop and implement appropriate solutions to these	D	

Table 7.1 Summary of results (continued)

General Training					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Prewett et al. 2013	Team training: lecture, several role plays, and guided discussion for feedback	Trauma resuscitation teams	Improvement of behavioural choices for teamwork in the trauma room. More effective responses to teamwork issues, but no affect in case of already a positive attitudes toward teamwork	D	
Stephens et al. 2016	Interprofessional training course: workshops, simulated a structured debriefing technique, facilitated discussion, and sustainability strategy	Perioperative practitioners	Improvement in team behaviours (communication, coordination, cooperation and back-up, leadership, situational awareness); recognizing different perspectives and expectations within the team; briefing and debriefing	D	
Webb et al. 2010	Emotional intelligence coaching: homework assignments, coaching sessions, goal setting	Family medicine	Decline in teamwork rating and no improvement on competences	D	
Table 7.1 Sur	mmary of results (continued)				
Tools: Struct	ures teamwork: SBAR				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Beckett et al. 2009	SBAR Collaborative Communication Education (e.g. didactic content, role-play, and an original DVD demonstrating traditional and SBAR communication)	Hospital paediatrics/ perinatal services department	Improvement in communication, collaboration, satisfaction, and patient safety outcomes	С	
Clark et al. 2009	PACT (Patient assessment, Assertive communication, Continuum of care, Teamwork with trust) Project, aimed at improving communication between hospital staff at handover: 2 communication tools based on SBAR: Handover prompt card & reporting template	Private hospital	improvement in communication, handover, and confidence in communicating with doctors	С	
Costa & Lusk 2017	SBAR educational session	Behaviour health clinicians in correctional facilities	Marginal improvement in communication and team structure	D	

Tools: Struct	ures teamwork: SBAR			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Donahue et al. 2011	EMPOWER project: an interdisciplinary leadership- driven communication program (Educating and Mentoring Paraprofessionals On Ways to Enhance Reporting) using SBAR	Hospital	Improvement in communication from paraprofessional staff to professional staff, no significant changes in rapid events reports	С
Martin et al. 2015	Huddles structured with SBAR with an educational session	Paediatric emergency department	Improvement in teamwork, communication, and nursing satisfaction	С
Randmaa et al. 2014	SBAR and implementation strategies (e.g. modified SBAR card, in-house training course, information material and observation)	Anaesthetic clinics	Improvement in between-group communication accuracy, safety climate, the proportion of incident reports due to communication errors	С
Renz et al. 2013	SBAR protocol and training	Nursing homes	Mixed results regarding the nurse satisfaction with nurse-medical provider communication	D
Rice et al. 2010	Interprofessional intervention: semi-scripted four step process during all patient-related interactions (i.e. name, role, issue, and feedback)	General internal medicine	No changes in communication and collaboration between health professionals	D
Sculli et al. 2015	Effective Followership Algorithm: 3Ws (what I see; what I'm concerned about; what I want), 4-Step Assertive Tool, Engage team, Chain of command	Paediatric and adult operating rooms	Improvement in safety culture, teamwork, team performance	С
Ting et al. 2017	SBAR Collaborative Communication Education: educational session, case-based discussion, video demonstration on traditional and SBAR communication	Obstetrics department	Improvement in teamwork climate, safety climate, job satisfaction, and working conditions	D
Weller et al. 2014	Video-intervention teaching SNAPPI tool: Stop the team; Notify of the patient's status; Assessment of the situation; Plan what to do; Priorities for actions; and Invite ideas	Anaesthesiology	Improvement in SNAPPI score, number of diagnostic options, information sharing. No significant improvement in information probe sharing and medical management (in intervention group)	C

Tools: Structures teamwork: Checklist					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Bliss et al. 2012	Comprehensive surgical safety checklist (using preoperative briefing and postoperative debriefing checklists) and a structured team training curriculum	Surgery	Decrease in 30-day morbidity. Cases with safety-compromising events (e.g. inadequate communication, decision- making), had higher rates of 30-day morbidity	В	
Bohmer et al. 2012	Modified perioperative surgical safety checklist	Operating room	Improvement in interprofessional coordination and communication	D	
Böhmer et al. 2013	Perioperative safety checklists	Anaesthesiology and traumatology	Improvement in verification of written consent for surgery, clear marking of the surgical site, time management, better informed about the patients, the planned operation, and the assignment of tasks during surgery in both short and long term. Decrease in communication over longer time periods.	В	
Cabral et al. 2016	Standardized, comprehensive time out and a briefing/debriefing process using surgical safety checklist	Surgery	Improvement of nurses' perception of communication. No significant improvement of surgeons and technologists perception of communication	С	
Calland et al. 2011	Surgical safety checklists (intervention group included a basic team training using a pre- procedural checklist)	Surgery	Improvement in team behaviour, defined as discrete, objective, observable shared communication behaviours; more likely to involve positive safety-related team behaviours such as case presentations, explicit discussions of roles and responsibilities, contingency planning, equipment checks, and post case debriefings; no significant differences in situational awareness	A	
Dabholkar et al. 2018	Customized surgical safety checklist	Surgery	Improvement in verification of patient's identity, awareness of operating team members' names and roles, practice of displaying radiological investigation during surgery, pre-check of equipment and communication	В	

Tools: Structures teamwork: Checklist					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Dubois et al. 2017	Person-centred endoscopy safety checklist (introduces during seminars and training)	Endoscopy unit	Improvement in quality of collaboration with nurses and perception. No differences in teamwork	D	
Erestam et al. 2017	Revised surgical safety checklist	Operating room	No significant change in teamwork climate. Lack of adherence to the checklist was detected	С	
Everett et al. 2017	Critical event checklists	Surgical daytime facility	No improvement in medical management or teamwork (during simulation)	С	
Gordon et al. 2014	Pre-procedure checklist	Cardiac catheterization laboratory	No improvement in complication rates, overall team and safety attitudes	С	
Hardy et al. 2018	Malignant hyperthermia checklist	Anaesthesiology	Improvement in non-technical skills in the experiment group. Higher self-reported stress in the experiment group	С	
Haugen et al. 2013	Surgical safety checklist	Operating room	Improvement in frequency of events reported and adequate staffing. No significant improvement in patient safety, teamwork within units, communication on error, hospital management promoting safety	В	
Haynes et al. 2011	Checklist-based surgical safety intervention	Operating rooms	Improvement in teamwork and safety climate	С	
Helmiö et al. 2011	Surgical safety checklist	Operating room	Improvement in verification of the patient's identity, awareness of the patient's medical history, medication and allergies, knowledge of the names and roles among the team members, discussion about possible critical events, recording postoperative instructions, communication between team members	В	
Jing & Honey 2016	Kobotic-assisted laparoscopic radical prostatectomy checklist	Operating room	Improvement in teamwork, time efficiency, higher confidence levels and more comprehensive operating room setup	D	
Kawano et al. 2014	Surgical safety checklist	Surgery	Improvement in the Safety Attitude Scores	С	

Tools: Structures teamwork: Checklist					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Kearns et al. 2011	Modified surgical safety checklist	Obstetric theatre	Improvement in interprofessional communication, familiarity with team members, and checklist compliance	С	
Kherad et al. 2018	Endoscopy checklist implementation (with lectures by quality officers)	Endoscopy	Improvement in teamwork and communication, patient perception of team communication and teamwork. No significant improvement in team perception	C	
Lepanluoma et al. 2014	Surgical safety checklist	Operating room	Improvement in communication between the surgeon and the anaesthesiologist. Safety-related issues were better covered. No improvement in awareness. Improvement in unplanned admission rates and number of wound complications	D	
Low et al. 2013	'Flow checklists' at high-risk points in the patient surgical journey, in addition to the surgical safety checklist	Ambulatory surgery centre	Improvement in the perception of patient safety	D	
Merrell et al. 2018	Emergency manual consisting of a set of crisis checklists or cognitive aids	Operating room	Enabled perceived effective team functioning through reducing stress, fostering a calm working environment and improvement teamwork and communication	D	
Mohammed et al. 2013	Obstetric safe surgery checklist	Anaesthetists and obstetricians	Improvement in communication of caesarean section grade (urgency) between obstetricians and anaesthetists	С	
Molina et al. 2016	Surgical safety checklists	Operating room	Improvement in respect, clinical leadership, assertiveness, coordination, and communication	A	
Nilsson et al. 2010	Pre-operative checklist during time-out	Operating room	Improvement in 'team feeling'	D	

Tools: Struct	ures teamwork: Checklist			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Norton et al. 2016	Novel paediatric surgical safety checklist	Operating room at paediatric hospital	Reduced complications and errors and improved patient safety, communication among team members, teamwork in complex procedures, efficiency in the operating room, prevented or averted an error or a complication	C
Papaconstan- tinou et al. 2013	Surgical safety checklist	Surgery	Improvement in the awareness of patient safety and quality of care, the perception of the value of and participation in the time-out process, surgical team communication, and in the establishment and clarity of patient care needs	В
Sewell et al. 2011	Educational program focused on using the surgical safety checklist	Orthopaedic surgery	Increase in checklist use, believe that the checklist improved team communication; checklist use was not associated with a significant reduction in early complications and mortality in patients undergoing orthopaedic surgery	В
Takala et al. 2011	Surgical safety checklist	Operating room	Improvement in confirming patient's identity, knowledge of names and roles among team members, discussing critical events, and fewer communication failures	Α
Tscholl et al. 2015	Anaesthesia pre-induction checklist, in addition to the surgical safety checklist	Anaesthesiology	Improvement in information exchange, knowledge of critical information, perception of safety in anaesthesia teams, perceived teamwork	A
Urbach et al. 2014	Surgical safety checklist	Operating room	Implementation is not associated with significant reductions in operative mortality or complications	В
White et al. 2017	Four-day pilot course for implementation of surgical safety checklist	Hospital (low-income setting)	Improvement in learning, behaviour and organisational change (not hierarchical culture)	D

Tools: Struct	Tools: Structures teamwork: (De)Briefing					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Berenholtz et al. 2009	Standardized one-page briefing and debriefing tool	Operating room	Improvement in interdisciplinary communication and teamwork	С		
Boet et al. 2011	Self-debriefing versus instructor debriefing	Hospital	Improvement in situational awareness, teamwork, decision- making, task management, total non-technical skills, regardless of the type of debriefing received	В		
Boet et al. 2013	Interprofessional within-team debriefing compared to an instructor-led debriefing	Operating room	Improvement in team performance regardless of the type of debriefing. No significant difference in the degree of improvement between within-team debriefing and instructor-led debriefing	С		
Einav et al. 2010	Pre-operative team briefings (briefing protocol and poster)	Operating room	25% reduction in the number of non-routine events when briefing was conducted and a significant increase in the number of surgeries in which no non-routine event was observed. Team members evaluated the briefing as most valuable for their own work, the teamwork, and patient safety	С		
Gleicher et al. 2017	Standardised handover protocol consisting of a handover content checklist and a 'sterile cockpit' time-out	Cardiovascular intensive care	Improvement in teamwork, content received and patient care planning	С		
Howe et al. 2014	Long-term care Team Talk program involved regularly scheduled 5-minute debriefing sessions at the end of the day shift led by a rotating schedule of certified nurse	Transitional care unit in long-term care facility	Improvement in co-worker and supervisor support, teamwork and communication, job demands and decision authority, characteristics of the unit and intent to leave/transfer unit	С		
Khoshbin et al. 2009	"07:35 huddles" (preoperative OR briefing following 4 elements) and "surgical time-outs" (pre- operative OR briefing following 9 elements)	Pediatric hospital	Especially for the nursing personnel, change the notion of individual advocacy to one of teamwork and being proactive about patient safety	С		
Lingard et al. 2008	Team briefing structured by a checklist	General surgery	Improvement in number of communication failures and proactive and collaborative team communication	С		

1001s: Struct	ures teamwork: (De) briefing			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
McLaughlin et al. 2014	Time-Out Process: 1) team member introductions, 2) safety statement by the time-out leader, 3) addition of two supplemental items to the institutional checklist, and 4) pre-incision Surgical Care Improvement Project measures	Neurosurgery in operating room	Improvement in the perception of patient safety, team spirit, voice safety concerns. Does not necessarily reinforce teamwork.	D
Nadler et al. 2011	Debriefings using video recordings	Neonatal resuscitation	Improvement in teamwork	С
Nundy et al. 2008	Preoperative briefings using a standardized format (with training session)	Operating room	Reduction in unexpected delays and communication breakdowns leading to delays	В
Paige et al. 2009	Pre-operative briefing protocol	Operating room	Improvement in preoperative briefing and overall team interaction; no significant improvement in procedure time	D
Pannick et al. 2017	Prospective clinical team surveillance (PCTS): structured daily interdisciplinary briefings to capture staff concerns, with organisational facilitation and feedback	Medical ward	Improvement in safety and teamwork climates, reduction in excess length of stay (eLOS)	В
Papaspyros et al. 2010	Pre-operative briefing with checklist and debriefing	Cardiac operating room	Improvement in communication	D
Skåre et al. 2018	Video-assisted, performance- focused debriefings	Delivery	Improvement in Neonatal Resuscitation Performance Evaluation (NRPE) score: group function/communication, preparation and initial steps and positive pressure ventilation	С
Steinemann et al. 2016	Structured physician-led briefing (using a checklist)	Trauma care	Improvement in T-NONTECH leadership scale (not the other domains) and task completions (not for all scenario's)	С
Wagner et al. 2014	Mental health huddles (similar to safety briefings) to support staff in discussing and managing client responsive behaviours	Long-term care	improvement in staff collaboration, teamwork, support, and communication	D

Tools: Struct	Tools: Structures teamwork: (De)Briefing				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Weiss et al. 2017	After events reviews (AER): assertiveness-specific AER (ASAER) versus teamwork- generic AER (TGAER)	Healthcare teams	Improvement in nurses speaking up following the ASAER in comparison to TGAER and higher levels of hierarchy-attenuating beliefs following the ASAER in comparison to TGAER	С	
Whyte et al. 2009	Structured preoperative team briefings (using a checklist)	Preoperative teams	Five types of negative events: the briefings could mask knowledge gaps, disrupt positive communication, reinforce professional divisions, create tension, and perpetuate a problematic culture	D	
Zausig et al. 2009	Two different training groups: one included extensive debriefing of NTS (resource management, planning, leadership and communication) and medical management and the other included a simpler debriefing that focused solely on medical management	Anaesthesiology	Improvement in non-technical skills; no differences between the groups	D	

Tools: Facilit	Tools: Facilitates teamwork: Rounds					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE		
Genet et al. 2014	Respiratory therapist (RT)-led interdisciplinary rounds using a scripted tool (with education session)	Neonatal ICU	Improvement in communication, teamwork, and timeliness of completing respiratory orders	В		
Henkin et al. 2016	Bedside rounding: inclusion of nurses in morning rounds with the medicine teams at the patients' bedside, using a checklist	General medicine inpatient teaching unit	Improvement in the perceptions of nurse-physician teamwork	С		
Li et al. 2018	Interprofessional Teamwork Innovation Model (ITIM): structured daily rounds	Academic medical centre	Improvement in communication among team members and overall time savings. Reduction in 30-day same-hospital readmissions, no impact on 30-day same-hospital ED visits or costs	В		

Tools: Facili	Tools: Facilitates teamwork: Rounds				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
O'Leary et al. 2010	Structured Inter-Disciplinary Rounds combined a structured format for communication and a forum for regular interdisciplinary meetings	Tertiary care teaching hospital	Improvement in teamwork climate in intervention group (compared to control group)	В	
O'Leary et al. 2011	Structured Inter-Disciplinary Rounds: combined a structured format for communication with a forum for regular interdisciplinary meetings	General medical unit in hospital	Improvement in quality of communication and collaboration with hospitalists, teamwork and safety climate	C	
O'Leary et al. 2015	Structured Interdisciplinary Rounds and prepared nurse– physician co-leadership	General medical units	Improvement in teamwork but no reduction in Adverse Events	С	
Young et al. 2017	Multidisciplinary Bedside Rounding Initiative, which included creating nursing availability, streamlining provider communication, and performance monitoring and feedback	Hospital	Improvement in teamwork climate, nurse job satisfaction, and early discharges	D	
Table 7.1 Sur	mmary of results (continued)				
Tools: Facili	tates teamwork				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Butler et al. 2018	Telemedicine technology in care delivery	Emergency care	No differences in teamwork between control and experiment groups. Higher workload in experiment group	В	
Chu- Weininger et al. 2010	Remote monitoring by intensivists using telemedicine technology (tele-ICU)	Intensive care	Improvement in teamwork climate and safety climate	В	
Doyle et al. 2016	Remote information technology (education session, teleconferences, web-based team case presentations)	Mental health services for older people	Improvement in professional development, perceived peer support, team building, cohesion, and reduce travel time	D	
Foo et al. 2015	Mobile task management tool (digitize patient flow and provide real-time visibility over clinical decision-making and task performance)	Acute general surgical service	Improvement in working efficiency of junior clinical staff	С	
Letchworth et al. 2017	MedNav; a decision support tool	Maternity teams	Improvement in teamwork	В	

Tools: Facilitates teamwork					
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
O'Connor et al. 2009	Using wireless e-mail in order to sent information-rich, specific, legible, and time-stamped messages	Intensive care	Improvement in communication, team relationships, staff satisfaction, and patient care	D	
Yeh et al. 2016	Ping-pong-type multidisciplinary reflective e-communication (within web-based integrated information platform)	Radiation oncology	Higher Timeliness, Notating convenience, Information completeness, Feedback convenience, Communication confidence, Communication effectiveness, Review convenience and overall satisfaction	С	

Tools: Trigge	Tools: Triggers teamwork				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Aberdeen & Byrne 2018	Concept mapping visually representing a patient's situation	Residential aged care facilities	Improvement in effectiveness of care planning and knowledge increase of dementia care	D	
Ainsworth et al. 2013	Door Communication Card (DCC) to improve goal alignment	Surgical ICU academic military medical	No improvement in goal alignment	D	
Bennett et al. 2015	Sharing clinical cases and stories about patients (during workshops)	Primary care clinical setting	Helped in bonding around their shared mission of patient- centred care, build supportive relationships, enhance compassion for patients, communicate and resolve conflict, better understand workflows and job roles, develop trust, and increase morale	D	
Daley et al. 2012	Clinical dashboard system	Acute elderly care	Improvement in access to information, communication and information-sharing, staff awareness, and data quality	D	
O'Neil et al. 2017	Thought for the Day (TOD) intervention; a short reflection on a piece of poetry, music, or religious writing	Inpatient palliative care	Improvement in perception of teamwork. Coming together as an interdisciplinary team for a time to reflect is valued	D	
Siegele 2009	The Daily Goals Tool (DGT) and Daily Goals Tool Reference (DGTR)	Surgical intensive care	Helps in simplifying complex tasks, improving teamwork, promoting effective communication and shared decision-making, and enhancing patient safety	D	

Tools: Triggers teamwork				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Stoller et al. 2010	Respiratory therapy (RT) business scorecard that compared target goals with actual monthly performance	Respiratory therapy departments	Improvement in teamwork among RT departments and outcomes	D

Organization	Organizational interventions: (Re)Design				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Barry et al. 2016	Behavioural Health Interdisciplinary Program (BHIP) team model as an innovative approach to transform VHA general outpatient mental health delivery, include holding daily huddles and longer weekly interdisciplinary team meetings	Veterans Health Administration mental health care	Improvement in teamwork and patient care and has potential to improve staff working relationships, communication, collaboration, morale, and veteran treatment consistency	D	
de Beijer et al. 2016	Clinical pathways: standardising treatment and communication methods, delegating tasks from medical specialists to nurses, and providing nurses with their own consultation room	Orthopaedic hand unit outpatient clinic	Improvement in the actual communication and collaborative problem-solving skills concerning standard patients	D	
Clements et al. 2015	Allocating the most senior nurse as team leader of trauma patient assessment and resuscitation	Emergency department	Improvement in understanding of their role, 'intimidating personality', and nursing leadership	С	
Deneckere et al. 2013	Care pathways: (1) Formative evaluation of the teams' performance before implementation, (2) Evidence- based KI, and (3) Training in pathway development	Acute hospital	Improvement in conflict management, team climate for innovation, level of organized care, risk of burnout, emotional exhaustion, and competence. No significant improvement in relational coordination	В	
Fernandez et al. 2010	Two models: The multifaceted Shared Care in Nursing (SCN) model of nursing care involved teamwork, leadership and professional development. In the Patient Allocation (PA) model one nurse was responsible for the care of a discrete group of patients	General medical and surgical wards in tertiary teaching hospital	The two models of care support most aspects of interdisciplinary and intra-disciplinary communication	С	

Organization	Organizational interventions: (Re)Design				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Fogel et al. 2016	Patient-focused primary care redesign	Continuity clinic settings	Improvement in teamwork training, teamwork among residents, perception of overall quality of care in clinic, and that physicians, nurses, and administrative staff worked together to optimize patient flow	C	
Frykman et al. 2014	Multi-professional teamwork involving changes in work processes, with task-generated feedback, managerial feedback, aimed at increasing inter- professional collaboration	Emergency department	Enabled teamwork	С	
Greene et al. 2015	Innovative compensation model: replaced fee-for-service payment with a largely team based, quality-focused payment, 40% of compensation was based upon the clinic-level quality performance, and an additional 10% was based upon the clinic-level patient's experience	Primary care	Mixed results: quality improvement for the team and less patient "dumping," or shifting patients with poor outcomes to other clinicians, but also lack of control and colleagues riding the coattails of higher performers. mixed results: greater interaction with colleagues, but also an increase in tension	С	
Hern et al. 2009	Quality improvement intervention: creation of team structures linking faculty advisors and residents with patients, intra-team management of office tasks, and the implementation of multidisciplinary team meetings	Family medicine	Improvement in perceptions of continuity of patient care, office efficiency, and team communication	С	
Hung et al. 2018	Redesign consisting of multiple workflow changes: (1) '5S' standardization of medical equipment, supplies and education materials in patient exam rooms, (2) redesign of call centre functions, (3) co-location of existing care teams and (4) redesign of care team roles and workflows	Ambulatory care primary care departments	Improvement in teamwork, participation in decisions to improve care by physicians, engagement among physicians and motivation among non- physicians staff	C	
O'Leary et al. 2009	Localizing physicians to specific patient care units	Hospital	Nurses and physicians were able to identify one another and communicated more frequently	В	

Organization	Jrganizational interventions: (Re)Design				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE	
Pan et al. 2017	An operating room (OR) assistant using an instructional supervision program	Operating room	Improvement in first cases that started on time, percentage of teamwork score and patient satisfaction	В	
Parush et al. 2017	Employ technological cognitive aids at ED	Emergency Department	Improvement in teamwork; overall communication, situational awareness (as measured by CTS and not SAGAT), and decision-making	D	
Pati et al. 2015	Decentralized unit operations and the corresponding physical design	Inpatient units	Potentially improvement in quality of work	D	
Stavroulis et al. 2013	Integrated theatre environment: a superior operating environment in which the laparoscopic equipment and multiple flat- screen monitors are permanently installed to be operational on demand inside the theatre	Operating room	Improvement in perceived efficiency, teamwork and stress levels	С	
Stepaniak et al. 2012	Fixed operating room (OR) teams for a day instead of OR teams that vary during the day	Operating room (bariatric surgery)	Reduced procedure durations and improved teamwork and safety climate, without adverse effects on patient outcomes	В	

Organizational interventions: Program				
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Basson et al. 2018	Multifaceted intervention consisting of monthly walking rounds by the director and an interactive learning session focused of feedback of culture data, educational training program, and unit-based program for safety	Veterans administration hospital leaders	No improvement on most items of the SAQ and AHRQ Hospital Safety Survey. Improvement in responding to errors and expressing disagreement with physicians. Decrease of perception of leadership's safety efforts and levels of staffing	D
Bunnell et al. 2013	For each identified risk area, agreements about roles, responsibilities and behaviours of each team member were made. Tools were developed and systems modified to enhance situational awareness and a shared mental model among team members, and to support implementation of the agreements	Ambulatory clinical oncology practice	Improvement in patient satisfaction scores regarding coordination of care, efficiency safety of care, more respectful behaviour, relationships among team members. No significant improvement in non- communication	С

Organization	nal interventions: Program			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Braithwaite et al. 2012	System-wide intervention promoting interprofessional collaboration; implementing educational workshops and seminars, feedback sessions, project, and other initiatives	Health professionals across entire health system	Most agreement on improvement in sharing of knowledge between professions and improved quality of patient care, and least agreement that between-professional rivalries had lessened and communication and trust between professions improved	В
Carney et al. 2011	Medical team training program: preparations, learning sessions, implementing projects including briefing and debriefing, coaching	Operating room in Veterans Health Administration	Improved perceptions of safety climate	В
Carney et al. 2011	Medical team training program: preparations, learning sessions, implementing projects including briefing and debriefing, coaching	Veterans Health Administration	Improvement in teamwork climate	В
Costello et al. 2011	OR Transformation Project: OR day redesign, workflow, human resources analysis, supply and technology, and quality of work life	Operating room	Improvement in work practices, recognition/ compensation, communication, commitment, physical/environmental safety, teamwork, and respect	С
Ginsburg & Bain 2017	Multifaceted intervention program to promote speaking up and teamwork consisting a role-playing simulation workshop, discussion briefings and other department-led initiatives such as 10-minute staff huddles	Emergency department and intensive care	Improvement in team climate score at follow-up	В
Hilts et al. 2013	The Quality in Family Practice (QIFP) program encompasses clinical and practice management using a comprehensive tool of family practice indicators	Academic primary care clinics	Improvement in understanding of team roles and relationships, teamwork, flattening of hierarchy through empowerment	D
Hsu et al. 2015	Multifaceted intervention included Comprehensive Unit- based Safety Program (CUSP), the daily goals communication tool, and 5 evidence- based practices (i.e. hand washing, using full-barrier precautions during the insertion of central venous catheters, cleaning the skin with chlorhexidine, avoiding the femoral site, and removing unnecessary catheters)	Adult intensive care	Improvement in safety climate, job satisfaction, and working conditions	В

Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Hsu et al. 2014	Team Resource Management (TRM) program: simulative learning workshop (e.g. lectures, videos, case-based interactive discussions), focus group interviews, develop TRM-based checklists, working sheets, and re- designed organ procurement and transplantation processes, video skill demonstration and training, case reviews and feedback activities	Hospital	No significant improvement on teamwork (i.e. teamwork framework, leadership, situational awareness, communication, mutual support); no error in communication or patient identification was noted	С
Je et al. 2013	Hospital-wide quality improvement program: forming committee to review the system, implemented a dedicated communication system, standardization of role, training, implementing a standard reporting system	Hospital	Improvement in safety attitude (i.e. sharing information, training, medical error reporting, safety climate, job satisfaction, communication, hospital management quality)	В
Kotecha et al. 2015	Quality Improvement Learning Collaborative Program: learning sessions, action periods to develop improvement plans, and summative congresses supported by QI coaches, teleconferences, and a web-based virtual office	Primary care	Improvement in trust and respect for each other's clinical, administrative roles, collegial relationships, collapse professional silos, communication, and interdisciplinary collaboration	D
Lin et al. 2018	Safety Program for Surgery: Comprehensive Unit-based Safety Program (CUSP) and individualized bundles of interventions	Hospitals	Improvement in overall perception/patient safety, teamwork across units, management- support patient safety, non-punitive response to error, communication openness, frequency of events reported, feedback/communication about error, organizational learning/continuous Improvement, supervisor/manager expectations and actions promoting safety, and teamwork within units	В

Organizatio	nal interventions: Program			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
McArdle et al. 2018	Safety Program for Perinatal Care (SPPC, adapted CUSP): TeamSTEPPS teamwork and communication framework and tools, applying safety science principles (standardization, independent checks, and learn from defects), and establishing an in situ simulation program	Labour and delivery	Improvement in the se of shoulder dystocia safety strategies, in situ simulation, teamwork and communication, standardization, learning from defects, and independent checks	В
McCulloch et al. 2017	Four-month safety improvement interventions, using teamwork training (TT), systems redesign and standardization (SOP), Lean quality improvement, SOP+TT combination, or Lean+TT combination	Operating room	TT: improvement in nontechnical skills and WHO compliance, but not technical performance. Systems interventions (Lean & SOP): improvement in nontechnical skills and technical performance, WHO compliance. Combined interventions: improvement in all performance measures except WHO time-out attempts, whereas single approaches improved WHO compliance less and failed to improve technical performance	В
Neily et al. 2010	Medical Team Training program: preparation, learning session, implementing briefings, debriefings and other projects (i.e. SBAR, Interdisciplinary rounds, Fatigue management), follow-up coaching	Surgical care in Veterans Health Administration	Improvement in teamwork, efficiency, avoiding an undesirable event	С
Neily et al. 2010	Medical Team Training program: preparation, learning session, implementing projects, follow-up coaching	Operating room in Veterans Health Administration	Lower surgical mortality and improvement in open communication and staff awareness	А
Pettker et al. 2011	Comprehensive obstetrics patient safety program: (1) obstetrics patient safety nurse, (2) protocol-based standardization of practice, (3) CRM training, (4) oversight by a patient safety committee, (5) 24-hour obstetrics hospitalist, and (6) anonymous event reporting system	Hospital	Improvement in proportion of staff members with favourable perceptions of teamwork culture, safety culture, job satisfaction, and management. No significant improvement in stress recognition	В

Organization	nal interventions: Program			
Authors (year)	Intervention	Setting	Outcome(s)	GRADE
Pitts et al. 2017	Comprehensive Unit-based Safety Program (CUSP): training, safety assessment, select safety priorities	Primary care	No significant improvement in safety climate and teamwork	D
Pronovost et al. 2008	Comprehensive Unit-based Safety Program including implementing CUSP (i.e. 6-step iterative process), daily goals communication strategy, and toolkit included materials for staff education, redesign of work processes, support of local opinion leaders, and evaluation of performance	Intensive care	Improvement in teamwork climate	В
Sexton et al. 2011	Comprehensive Unit-based Safety Program (CUSP): educate teams, identify, prioritize, and eliminate patient safety hazards, senior leader's role, tools for learning and improving communication	Intensive care	Improvement in safety climate	В
Stapley et al. 2017	The Situation Awareness For Everyone (SAFE) programme: huddle, SBAR, and paediatric early warning systems (PEWS)	Clinical wards	Improvement in awareness of important issues, communication, teamwork, and a culture of increased efficiency, anticipation and planning on the ward. But added pressure on staff time and workload, and the potential for junior nurses to be excluded from involvement	D
Timmel et al. 2010	Comprehensive Unit-Based Safety Program (CUSP) including 6 steps: Science of safety training educational curriculum, identify safety hazards, Senior executive partnership, Learn from defects, Implement improvement tools, such as team-based goals sheet, including nurses on rounds to form an interdisciplinary team	Surgical inpatient units	Improvement in safety climate, teamwork climate, and nurse turnover rates	В
Wolf et al. 2010	Medical Team Training program: preparation, classroom learning session, checklist-guided briefings and debriefings, formation of a problem-solving Executive Committee, follow-up and feedback	Operating room in Veterans Health Administration	Improvement in case delays, mean case score, frequency of preoperative delays, hand- off issues, equipment issues/ delays, perceived management and working conditions. No significant improvement in teamwork climate, safety climate, job satisfaction, stress recognition	В

Interventions	N	Description
1. Training	174	"A systematic process through which a team is trained to master and improve different aspects of team functioning" (Buljac-Samardzic et al., 2010).
1.1 Principle-based training		
a CRM-based training	40	"Training based on a management concept used in the aviation industry to improve teamwork. CRM encompasses a wide range of knowledge, skills and attitudes including communication, situational awareness, problem solving, decision-making and teamwork " (Buljac-Samardzic et al., 2010).
b. TeamSTEPPS	28	A specific set of strategies and techniques, aimed at optimizing patient outcomes by improving communication and teamwork skills among healthcare professionals (Agency for Healthcare Research and Quality, 2020).
1.2 Method-based training: Simulation-based training	69	"Training that recreates characteristics of the real world" (Buljac-Samardzic et al., 2010).
1.3 General team training	37	General team training includes studies that each have a unique combination of principles and learning methods.
2. Tools	83	Specific instruments that teams use to improve teamwork (Buljac-Samardzic et al., 2010).
2.1 Structuring tools		Tools that are used to partly standardize the process of team interaction
a. SBAR	11	The SBAR (Situation, Background, Assessment, Recommendation) is a framework for communication between team members about a patient's condition (Institute for Healthcare Improvement, 2020).
b. (De)briefing checklist	51	A tool that creates an opportunity for professionals to systematically communicate and discuss (potential) issues before or after delivering care to a patient, based on a structured format of elements/topics'; checklist.
c. Rounds	7	A structured interdisciplinary meeting around a patient.
2.2 Facilitating tools	7	Tools (often technology) that facilitate communication between team members.
2.3 Triggering tools	7	Tools that provide information (e.g., dashboards) to incentivize team interaction
3. Organisational (re)design	16	Design or redesign of organisational structures with the aim of improving team processes and team functioning.
4. Programme	24	A combination of interventions (training, tools, and/or organisational (re)design) bundled in a program that aims to improve team functioning
Total	297	

Table 7.2. Categorisation of results

Overall findings

Type of intervention: The majority of studies evaluated a training. Simulation-based training is the most frequently researched type of team training.

Setting: Most of the articles researched an acute hospital setting. Examples of acute hospital settings are the emergency department, operating theatre, intensive care, acute elderly care, and surgical unit. Less attention was paid to primary care settings, nursing homes, elderly care, or long-term care in general.

Outcome: Interventions focused especially on improving non-technical skills, which refer to cognitive and social skills such as team working, communication, situational awareness, leadership, decision-making, and task management (Shields & Flin, 2013). Most studies relied on subjective measures to indicate an improvement in team functioning, with only a few studies (also) using objective measures. The Safety Attitude Questionnaire (SAQ) and the Non-Technical Skills (NOTECHS) tool are frequently used instruments to measure perceived team functioning.

Quality of Evidence: A bulk of the studies had a low level of evidence. A pre- and post-study is a frequently used design. In recent years, an increasing number of studies has used an action research approach, which often creates more insight into the processes of implementing and tailoring an intervention than the more frequently used designs (e.g., RCT and pre-post surveys). However, these valuable insights are not fully appreciated within the GRADE scale.

The findings per category will be discussed in greater detail in the following paragraphs.

Training

CRM and TeamSTEPPS are well-known **principle-based trainings** that aim to improve teamwork and patient safety in a hospital setting. Both types of training are based on similar principles.

CRM is often referred to as a training intervention that mainly covers non-technical skills such as situational awareness, decision-making, teamwork, leadership, coping with stress, and managing fatigue. A typical CRM training consists of a combination of information-based methods (e.g., lectures), demonstration-based methods (e.g., videos), and practice-based methods (e.g., simulation, role playing) (O'Dea, O'Connor, & Keogh, 2014). However, CRM has a management concept at its core that aims to maximize the use of all available resources (i.e., equipment, time, procedures, and people) (Lauber, 1984). CRM aims to prevent and manage errors through avoiding errors, trapping errors before they are committed, and mitigating the consequences of errors that are not trapped (Helmreich, Merritt, & Wilhelm, 1999). Approximately a third of CRM-based trainings include the development, redesign or implementation of learned CRM techniques/tools (e.g., briefing, debriefing, checklists) and could therefore also be categorized in this review under programme (Gore, Powell, Baer, & Sexton, 2009; Haerkens, Kox, Noe, van, & Pickkers, 2017; Hefner et al.,

2017; Morgan, Pickering et al., 2015; Ricci & Brumsted, 2012; Savage et al., 2017; Sax, Browne, & Mayewski, 2009; Schwartz et al., 2017; Sculli et al., 2013).

The studies show a high variety in the content of CRM training and in the results measured. The majority of the studies claim an improvement in a number of non-technical skills that were measured, but some also show that not all non-technical skills measured were improved (Hicks, Kiss, Bandiera, & Denny, 2012; LaPoint, 2012; Tschannen, McClish, Aebersold, & Rohde, 2015). Moreover, the skills that did or did not improve differed between the studies. A few studies also looked at outcome measures (e.g., clinical outcomes, error rates) and showed mixed results (McCulloch et al., 2009; Morgan, Hadi et al., 2015; Müller et al., 2009). Notable is the increasing attention towards nursing CRM, which is an adaptation of CRM to nursing units (Sculli et al., 2015; Tschannen et al., 2015). Most studies delivered a low to moderate quality level of evidence. Although most studies measured the effect of CRM over a longer period of time, most time periods were limited to one or two evaluations within a year. Savage et al. (Savage et al., 2017) and Ricci et al. (2012) (Ricci & Brumsted, 2012) note the importance of using a longer time period.

As a result of experienced shortcomings of CRM, Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) has evolved (since 2006). TeamSTEPPS is a systematic approach designed by the Agency for Healthcare Research and Quality (AHRQ) and the Department of Defence (DoD) to enhance teamwork skills that are essential to the delivery of quality and safe care. Some refer to TeamSTEPPS as 'CRM and more'. Team-STEPPS provides an approach on preparing, implementing, and sustaining team training. It is provided as a flexible training kit and facilitates in developing a tailored plan. It promotes competencies, strategies, and the use of standardized tools on five domains of teamwork: team structure, leadership, communication, situational monitoring, and mutual support. In addition, TeamSTEPPS focuses on change management, coaching, measurement, and implementation. Notable is that even though the TeamSTEPSS training is most likely to differ across settings as it needs to be tailored to the situational context, articles provide limited information on the training content. All studies report improvements in some non-technical skills (e.g., teamwork, communication, safety culture). Combining non-technical skills with outcome measures (e.g., errors, throughput time) seemed more common in this category. Half of the studies delivered a moderate to high quality of evidence.

Simulation-based training uses a specific method as its core namely, simulation, which refers to 'a technique to replace or amplify real-patient experiences with guided experiences, artificially contrived, that evokes or replicates substantial aspects of the real world in a fully interactive manner' (Aggarwal, Mytton, & Derbrew, 2010). The simulated scenarios that are used can have different forms (e.g., in situ simulation, in centre simulation, human actors, mannequin patients) and are built around a clinical scenario (e.g., resuscitation, bypass, trauma patients) aiming to improve technical and/or non-technical skills (e.g., interprofessional collaboration, communication). We only identified studies in a hospital setting, which

were mostly focussed on an emergency setting. All studies reported improvements in some non-technical skills (e.g., teamwork behaviour, communication, shared mental model, clarity in roles and responsibilities). In addition, some studies report non-significant changes in non-technical skills (Arora et al., 2014; Lee, Allen, & Daly, 2012; Meurling, Hedman, FellÁ¤nder-Tsai, & Wallin, 2013; Nicksa, Anderson, Fidler, & Stewart, 2015; Siassakos et al., 2011). Some studies also looked at technical skills (e.g., time spend) and presented mixed results (Fouilloux, Gsell, Lebel, Kreitmann, & Berdah, 2014; Rubio-Gurung et al., 2014; Steinemann et al., 2011; Stocker et al., 2012). 69 studies focused on simulation-based training, of which 16 studies delivered a moderate to high quality of evidence.

General team training does not focus on one specific training principle or method. It often contains multiple educational forms such as didactic lectures, interactive sessions, and online modules. General team training focuses on a broad target group and entails for example team building training, coaching training, and communication skills training. Due to the broad scope of this category, high variation in outcomes is noted, although many positive outcomes were found. Most studies have a low to very low level of evidence.

Tools

Tools are instruments that could be implemented relatively independently in order to **structure**, **facilitate** or **trigger** teamwork.

Structuring tools

Teamwork can be structured by using the structured communication technique **SBAR** (Situation, Background, Assessment, and Recommendation), **(de)briefing checklists,** and **rounds**.

SBAR is often studied in combination with strategies to facilitate implementation, such as didactic sessions, training, information material, modifying SBAR material (e.g., cards) (Beckett & Kipnis, 2009; Costa & Lusk, 2017; Martin & Ciurzynski, 2015; Randmaa, MÁ¥rtensson, Swenne, & EngstrÁ¶m, 2014; Renz, Boltz, Wagner, Capezuti, & Lawrence, 2013; Ting, Peng, Lin, & Hsiao, 2017). In addition, this subcategory entails communication techniques similar or based on SBAR (Clark, Squire, Heyme, Mickle, & Petrie, 2009; Donahue, Miller, Smith, Dykes, & Fitzpatrick, 2011; Rice et al., 2010; Sculli et al., 2015; Weller et al., 2014). One study focused on nursing homes, while the remaining studies were performed in a hospital setting. Most studies found improvements in communication; however, a few found mixed results (Renz et al., 2013; Rice et al., 2010). Only (very) lowlevel evidence studies were identified.

Briefings and debriefings create an opportunity for professionals to systematically communicate and discuss (potential) issues before or after delivering care to a patient, based on a structured format of elements/topics or a checklist with open and/or closed-end questions. CHAPTER 7

Studies on (de)briefing checklists often evaluate the implementation of the World Health Organization surgical safety checklist (SSC), a modified SSC, SSC-based checklist, or a safety checklist in addition to the SSC. The SSC consists of a set of questions with structured answers that should be asked and answered before induction of anaesthesia, before skin incision, and before the patient leaves the operating theatre. In addition, several studies presented checklists aiming to better manage critical events (Bereknyei Merrell et al., 2018; Everett et al., 2017; Hardy et al., 2018). Only one study on SSC was conducted outside the surgery department/ operating theatre (i.e., cardiac catheterization laboratory (Gordon et al., 2014)). However, similar tools can also be effective in settings outside the hospital, as shown by two studies that focused on the long-term care setting (Howe, 2014; Wagner et al., 2014). Overall, included studies show that (de)briefing checklist help improve a variety of non-technical skills (e.g., communication, teamwork, safety climate) and objective outcome measures (e.g., reduced complications, errors, unexpected delays, morbidity). At the same time, some studies show mixed results or are more critical of its (sustainable) effect (Böhmer et al., 2013; Urbach, Govindarajan, & Saskin, 2014). Whyte et al. (2008) pointed out the complexity of this intervention by presenting five paradoxical findings: team briefings could mask knowledge gaps, disrupt positive communication, reinforce professional divisions, create tension, and perpetuate a problematic culture. The quality of evidence varied from high to very low (e.g., Whyte et al., 2008), and approximately one third presented a high or moderate quality of evidence. Debriefings can also be used as part of a training, aiming to provide feedback on trained skills. Consequently, some articles focused on the most suitable type of debriefing in a training setting (e.g., video-based, self-led, instructor led) (Boet, Sylvain et al., 2011; Boet, S. et al., 2012; Nadler, Sanderson, Van Dyken, Davis, & Liley, 2011; Zausig et al., 2009) or debriefing as reflection method to enhance performance (Skåre et al., 2018; Weiss et al., 2017).

Rounds can be described as structured interdisciplinary meetings around a patient. Rounds were solely researched in hospital settings. Five studies found improvements in nontechnical skills, one study in technical skills, and one study reported outcomes but found no improvement. Three studies presented a moderate level of evidence, and the others presented a (very) low level.

Facilitating tools

Teamwork can be facilitated through technology. Technology, such as telecommunication, facilitates teamwork as it creates the opportunity to involve and interact with professionals from a distance (Butler et al., 2018; Chu-Weininger et al., 2010; Doyle, Jackson, Loi, Malta, & Moore, 2016). Technology also creates opportunities to exchange information through information platforms (O'Connor, Friedrich, Scales, & Adhikari, 2009; Yeh et al., 2016). Most studies found positive results for teamwork. Studies were performed in a hospital setting and presented a level of evidence varying from moderate to very low.

Triggering tools

Teamwork could be triggered by tools that monitor and visualise information, such as (score) cards and dashboards (Aberdeen & Byrne, 2018; Ainsworth, Pamplin, Rn, Linfoot, & Chung, 2013; Daley, Richardson, James, Chambers, & Corbett, 2013; Siegele, 2009; Stoller et al., 2010). The gathered information does not echo team performance but creates incentives for reflecting on and improving teamwork. Team processes (e.g., trust, reflection) are also triggered by sharing experiences, such as clinical cases and stories, thoughts of the day (Bennett, Hassinger, Martin, Harris, & Gold, 2015; O'Neil, Lyndale, Szakatis, & Fitzgerald, 2017). All seven studies showed improvements in non-technical skills and had a very low level of evidence.

Organizational (re)design

In contrast with the previous two categories, organizational (re)design is about changing organizational structures. Interventions can be focused on several elements within a healthcare organization, such as the payment system (Greene, Kurtzman, Hibbard, & Overton, 2015) and the physical environment (Stavroulis, Cutner, & Liao, 2013) but are most frequently aimed at standardization of processes in pathways (de Beijer, Hansen, Stilling, & Jakobsen, 2016; Deneckere et al., 2013) and changing roles and responsibilities (Bunnell et al., 2013; Clements, Curtis, Horvat, & Shaban, 2015; Fernandez, Tran, Johnson, & Jones, 2010; O'Leary et al., 2009a; Pati, Harvey, Redden, Summers, & Pati, 2015), sometimes by forming dedicated teams or localizing professionals to a certain unit or patient (Fogel, Warrick, Finkelstein, & Klein, 2016; Frykman, Hasson, Athlin, & von, 2014; O'Leary et al., 2009b; Stepaniak et al., 2012). Most studies found some improvements of non-technical skills; however, a few found mixed results. Only four studies had a moderate level of evidence, and the others had a (very) low level.

Programme

A programme most frequently consists of a so-called Human Resource Management bundle that combines learning and educational sessions (e.g., simulation training, congress, (Hsu & Marsteller, 2015a; Pronovost et al., 2008a; Timmel et al., 2010a) colloquium), often multiple tools (e.g., rounds, SBAR), and/or structural intervention (e.g., meetings, standardization)(Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010)(Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010)(Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010) (Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010)(Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010; Neily, Mills, Lee et al., 2010; Neily, Mills, Lee et al., 2010)(Je et al., 2014; Kotecha et al., 2015; Magrane, Khan, Pigeon, Leadley, & Grigsby, 2010; Neily, Mills, Lee et al., 2010). Moreover, a programme frequently takes the organizational context into account: developing an improvement plan and making choices tailored to the local situation. A specific example is the "Comprehensive Unit-Based Safety Program" (CUSP) that combines training (i.e., science of safety training educational curriculum, identify safety hazards, learn from defects) with the implementation of tools (e.g., team-based goals sheet), and structural intervention (i.e., senior executive partnership, including nurses on rounds, forming an interdisciplinary team) (Hsu et al., 2015; Pronovost et al., 2008; Timmel et al., 2010). Another example is the Medical Team Training (MTT) programme that consists of three stages: (1) preparation and follow-up, (2) learning session, (3) implementation and follow-up. MTT combines training, implementation of tools (briefings, debriefing, and other projects) and follow-up coaching (Carney et al., 2011a; Carney et al., 2011b; Neily et al., 2010a; Neily et al., 2010b). MMT programmes are typically based on CRM principles, but they distinguish themselves from the first category by extending their programme with other types of interventions. Most studies focus on the hospital setting, with the exception of the few studies performed in the primary care, mental health care, and healthcare system. Due to the wide range of programs, the outcomes were diverse but mostly positive. The quality of evidence varied from high to very low.

DISCUSSION

This systematic literature review shows that studies on improving team functioning in health care focus on four types of interventions: training, tools, organizational (re)design, and programmes. Training is divided in principle-based training (subcategories: CRM-based training and TeamSTEPPS), method-based training (simulation-based training), and general team training. Tools are instruments that could be implemented relatively independently in order to structure (subcategories: SBAR, (de)briefing checklists, and rounds), facilitate (through communication technology), or trigger teamwork (through information provision and monitoring). Organizational (re)design focuses on intervening in structures, which will consequently improve team functioning. Programmes refer to a combination of different types of interventions.

Training is the most frequently researched intervention and is most likely to be effective. The majority of the studies focused on the (acute) hospital care setting, looking at several interventions (e.g., CRM, TeamSTEPPS, simulation, SBAR, (de)briefing checklist). Long-term care settings received less attention. Most of the evaluated interventions focused on improving non-technical skills and provided evidence of improvements, objective outcome measures also received attention (e.g., errors, throughput time). Looking at the quantity and quality of evidence, principle-based training (i.e. CRM and TeamSTEPPS), simulation-based training, and (de)briefing checklist seem to provide the biggest chance of reaching the desired improvements in team functioning. In addition, programmes, in which different interventions are combined, show promising results for enhancing team functioning. Not

only the category programmes exemplifies this trend, but is also seen in principle-based training (i.e. CRM-based and TeamSTEPPS).

Because this review is an update of our review conducted in 2008 (and published in 2010) (Buljac-Samardzic et al., 2010), the question of how the literature evolved in the last decade arises. This current review shows that in the past ten years significantly more research has focused on team interventions in comparison to the previous period. However, the main focus is on a few specific interventions (i.e., CRM, simulation, (de) briefing checklist). Nevertheless, an increasing number of studies are evaluating programmes in which several types of interventions are combined.

Training: There has been a sharp increase in research studying team training (from 32 to 173 studies). However, the majority of these studies still look at similar instruments, namely, CRM-based and simulation-based training. TeamSTEPPS is a standardized training that has received considerable attention in the past decade. There is now a relatively strong evidence for the effectiveness of these interventions, but mostly for the (acute) hospital setting.

Tools: There is also a substantial increase (from 8 to 84 studies) in studies on tools. Again, many of these studies were in the same setting (acute hospital care) and focused on two specific tools, namely, the SBAR and (de)briefing checklist. Although the level of evidence for the whole category tools is ambiguous, there is relatively strong evidence for the effectiveness of (de)briefing checklist. Studies on tools that facilitate teamwork ascended the past decade. There is limited evidence that suggests these may enhance teamwork. The dominant setting was again hospital care, though triggering tools were also studied in other settings such as acute elderly care and clinical primary care. Moreover, most studies had a (very) low quality of evidence, which is an improvement compared to the previous review that solely presented (very) low level of evidence.

Organizational (re)design: More attention is paid to organizational (re)design (from 8 to 16 studies). Although the number of studies on this subject has increased, there still remains unclarity about its effects because of the variation in interventions and the mixed nature of the results.

Programmes: There seems to be new focus on a programmatic approach in which training, tools, and/or organizational (re)design are combined, often focused around the topic patient safety. The previous review identified only one such study; this research found 24 studies, not including the CRM studies for which some also use a more programmatic approach. There seems to be stronger evidence that this approach of combining interventions may be effective in improving teamwork.

Limitations

The main limitation of this review is that we cannot claim that we have found every single study per subcategory. This would have required per subcategory an additional systematic review or an umbrella review, using additional keywords. As we identified a variety of literature reviews, future research should focus on umbrella reviews in addition to new systematic literature reviews. Note that we did find more studies per subcategory, but they did not meet our inclusion criteria. For example, we excluded multiple studies evaluating surgical checklists that did not measure its effect on team functioning but only on reported errors or morbidity. Although this review presents all relevant categories to improve team functioning in health care organizations, those categories are limited to team literature and are not based on related research fields such as integrated care and network medicine. Another limitation is that we excluded grey literature by only focusing on articles written in English that present empirical data and were published in peer-reviewed journals. Consequently, we might have excluded studies that present negative or non-significant effects of team interventions, and such an exclusion is also known as publication bias. In addition, the combination of the publication bias and the exclusion of grey literature has probably resulted in a main focus on standardized interventions and a limited range of alternative approaches, which does not necessarily reflect practice.

Implication for future research

This review shows the major increase in the last decade in the number of studies on how to improve team functioning in health care organizations. At the same time, it shows that this research tends to focus around certain interventions, settings, and outcomes. This helped to provide more evidence but also left four major gaps in the current literature. First, less evidence is available about interventions to improve team functioning outside the hospital setting (e.g., primary care, youth care, mental health care, care for disabled people). With the worldwide trend to provide more care at home, this is an important gap. Thereby, team characteristics across health care settings vary significantly, which challenges the generalizability (Lemieux-Charles & McGuire, 2006). Second, little is known about the long-term effects of the implemented interventions. We call for more research that monitors the effects over a longer period of time and provides insights into factors that influence their sustainability. Third, studies often provide too little information about the context. To truly understand why a team intervention affects performance and to be able to replicate the effect (by researchers and practitioners), detailed information is required related to the implementation process of the intervention and the context. Fourth, the total picture of relevant outcomes is missing. We encourage research that includes less frequently used outcomes such as well-being of professionals and focuses on identifying possible deadly combinations between outcomes.

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CHAPTER 8

Implementing a web-based social network intervention for elderly patients with multimorbidity: lessons-learned

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ABSTRACT

Background: Elderly patients with multimorbidity are more and more expected to selfmanage their health. Individuals in their social network (e.g. family, friends, neighbours) play an important role with regard to their self-management support, but the size of the network and type of support differs between patients. Self-management interventions could benefit by taking the broader context of support potential of social network sources into consideration. To develop effective interventions, a first step is to identify the social network members and their support potential. This study describes and evaluates the implementation of an web-based tool (NetworkMAP) that was designed to enable elderly patients to visualise their social network and gain more insight into the potential support in their network.

Methods: The intervention period was five months. The intervention was implemented at a patient's home and on their personal electronic device (n=17). Data was collected by observations during the implementation (T0), interviews at T0, T1 (six weeks) and T2 (five months) on the usage and relevance of the tool and by keeping track of logdata on the actual usage of the tool.

Results: Elderly patients have different types of networks. Most participants have a family centric network (with an informal caregiver) and have frequent contact with their network members. The usage of the tool decreased in the intervention period for multiple reasons, primarily the deteriorating health situation of the participant. The participants' and researchers' reflection on the implementation showed insights into barriers and facilitators of implementing a technological tool.

Discussion and conclusion: Patients found it valuable to visual their social network, though there was little usage of the tool. Barriers and facilitators on the participant level and the technology level can be identified that can be taken into consideration when implementing a technological tool for elderly patients. When implementing technological tools for elderly patients it is first important that the aim of intervention, the design and the (technological) means used are in balance. Second, integrating new tools into existing tools that elderly patients are familiar with could increase their acceptance and usage of the tool.

INTRODUCTION

In the last decades, elderly patients with multimorbidity living in western European countries are more and more expected to age at home and take on more responsibility and self-manage their health situation (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Hengelaar et al., 2016). Though primary care professionals, such as a general practitioner and home care nurses, play a central role in delivering long-term care for these patients, research shows that with regard to supporting elderly patients in their self-management skills they still play a limited role (Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016). In practice, these professionals are mainly focused on illness related support (e.g. understanding treatment plans and symptoms), and less on emotional or practical support (Rogers et al., 2016). Instead, individuals in the social network of elderly patients such as family, friends and community groups play a more extensive role with regard to self-management support. Their support can range from illness related support (e.g. making and supporting during medical appointments) to everyday support (e.g. housekeeping, grocery shopping) or and/or emotional support (e.g. listening, companionship or comforting) (Kennedy, Vassilev, James, & Rogers, 2015; Rogers et al., 2016). Patients with limited support from their social network are shown to be less competent in understanding or managing their chronic condition(s), dealing with daily problems and show poorer health outcomes (Nutbeam, 2008; Protheroe, Nutbeam, & Rowlands, 2009; Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014). Given the importance of social network support for self-management, self-management interventions could benefit from not solely focusing on the patient's behaviour, but on the broader context taking the support potential of social network sources for into consideration. Identifying the strength of patients' social network and the potential resources for self-management support may lead to further development of self-management interventions that focus on mobilising potential sources for support.

Research on the social network of patients with multimorbidity shows that different types of social networks exist (figure 8.1) (Keating & Dosman, 2009; Kennedy et al., 2015; Vassilev et al., 2014).

Some of these network types are shown to have a more positive impact on providing the support that patients need to live with and self-manage their condition than others (Kennedy et al., 2015; Rogers et al., 2016). Therefore, self-management intervention programmes benefit from not solely focusing on the patient's behaviour, but on the broader context taking the potential of social network sources into account as well. In practice, primary care professionals often do not mobilise potential network sources for self-management due to a lack of understanding and recognizing resources within the social network (Kennedy et al., 2015; Vassilev, Rogers, Kennedy, Oatley, & James, 2019). In addition, also patients themselves need to realise that self-managing your own health situation also implies self-directed social support, meaning that patients themselves need to invest in maintaining and developing reciprocal relationships with their social network (Kennedy et al., 2015; Vassilev et al., 2019).

Figure 8.1. Social network types



To develop effective interventions in which resources and support for self-management are mobilized and deployed by primary care professionals as well as patients themselves, a first step is to identify the social network members and their support potential.

For this purpose a web-based tool named NetworkMAP (Network – mobilizing active partnerships) was developed. This chapter describes the implementation process of this tool. NetworkMAP was designed and implemented to enable elderly patients to map their social network and gain more insight for patients as well as professionals into the potential support of their network. A study on a similar tool (Kennedy et al., 2015) shows that mapping your social network could lead to deepening of existing relationships and support resources (Vassilev et al., 2019).

The aim of this chapter is two-fold. First, we explore the network types of elderly patients with multimorbidity living at home. Second, we reflect on the perceived usefulness, relevance and acceptance of the NetworkMAP tool, as well the implementation process from the perspectives of the elderly patients and the research team. We focus on the facilitators and barriers of implementing a tool with elderly patients with multimorbidity, resulting in lessons-learned.

METHODS

The intervention

NetworkMAP was developed to be a digital web-based intervention to increase elderly patients' insight into their social support network. The intervention was specifically designed for chronically ill elderly patients who, because of their condition, often receive care for multiple professionals and/or their social network. This study was part of a quantitative study on the interaction between elderly patients, their informal caregivers and the most involved home care nurse. NetworkMAP was added to an existing tool named 'HalloZorg', which is a website and tool designed to assist elderly in organising daily care. The tool consisted of functions such as an online agenda, chatting and sharing photos, writing daily journals and a daily timeline of medical appointments. The elderly patients could create a free account and share this account with preferred individuals in their social network. Moreover, elderly patients were already registered at HalloZorg, increasing the opportunity of a broad use of NetworkMAP in the future. The research team collaborated with the IT organisation that created HalloZorg (i.e. ConnectedCare) for the IT aspects of the design of NetworkMAP and compatibility with the HalloZorg website.

Participants

The study was conducted in collaboration with a large home care organization in the southwestern region of the Netherlands. All participants received home care from this home care organization.

The selection and inclusion process of the participants consisted of multiple phases. In the first phase, the home care organization randomly selected 2000 patients from their database. For this selection, the following criteria were set: (a) patients were aged 60 years or older and (b) received home care at least two days per week for six months or longer. In the second phase, the home care organisation send an information letter regarding the purpose of the study and a consent form to share their contact details with the research team. In phase three, patients who consented were phoned by the primary researcher and two trained research assistants and were asked if they were still willing to participate in the study. Patients were also asked whether they had access to a personal computer, laptop or tablet, understood the basic use of the device and were willing to use the device to create their personal NetworkMAP. Only patients who to a personal electronic device were eligible participants to the study. This was important to enhance the engagement of the participants in the use of the NetworkMAP implementation process but more importantly to support the use of the tool in their daily life. In the last phase, when patients agreed to participation, house visits were planned. In total, twenty patients agreed to participate. However, during the first house visits at T0, three patients decided to drop-out because of the severity of their illness. Therefore, seventeen patients created their personal NetworkMAP at T0.

At T1, another eight patients dropped out due to the severity of their condition or a decreased lack of interest and relevance of the intervention. Thus, nine of the twenty elderly patients participated during the whole intervention period.

Intervention implementation

Each patient was visited at their home by the primary researcher (T0), who acted as a facilitator explaining the elements of the tool and guiding the participants through the process of creating the first version of their NetworkMAP. The process was designed to take between 20 to 40 minutes and consisted of multiple consecutive steps. First, the primary researcher explained the elements of the tool using a flyer with a quick start guide (figure 8.2). This guide also contained information on for example how to create a personal account and how to make changes to their created social network. The content and lay-out of the guide was designed to be suitable to the elderly participants for example by using a larger font, contrasting colours and pictures (figure 8.2). All participants received a copy of the guide. Second, the primary researcher sat together with the participant behind their personal electronic device and guided them through the process of creating a personal account. Participants were asked to go to the website of HalloZorg and fill in some personal details (i.e. name, age and email address). After filling in their email address, participants received a link in their email account to filling in a password and therefore creating a personal account. At all times, the login details of each participant were not known to the primary researcher.

In NetworkMAP, a distinction was made between four types of network members (figure 8.3). The category 'others' could for example entail neighbours, pets or community groups. The distinction was based on other research on social networks of elderly patients and was made to(a) explore elderly patients' everyday relationships and (b) help them become conscious and reflexive of the size and support of their network (Kennedy et al., 2015; Rogers et al., 2016).

The process of creating a personalized NetworkMAP started with identifying their network members and the type of support they received from each social network member. In line with previous research on elderly patients' social networks, the type of support could be (a) illness-related support (e.g. taking medications, making medical appointments), (b) everyday support (e.g. housekeeping, support in activities related to exercise and diet) and (c) emotional support (e.g. comforting when anxious, companionship and listening) (Kennedy et al., 2015; Rogers et al., 2016).

Then, participants were asked to move their social network members to one of the categories and place each member closer or further from the centre (patient X), based on the participant's assessment of the subjective importance of each social network member (figure 8.4). The closer to the centre, and thus to the patient, the more important that network members was considered and vice versa. This method helped patients become more conscious of their social network and the contributions of each individual network member. Also, it acted as a starting point for discussion on how the possible extent existing support or access new sources for more or different type of support.

After discussing their social network, patients were informed that they could use and revise their social network themselves in the upcoming weeks and would be contacted after 6 weeks.

Figure 8.2. Quick start guide

Quick start guide for HalloZorg & NetworkMAP





With the HalloZorg tool you can organize your daily care in one place. The NetworkMAP tool has been recently added to HalloZorg as part of an academic research project.

In this quick start guide, we will explain how to use HalloZorg and NetworkMAP to gain more oversight over your social support network.

Inloggen

Creating a personal account

On the website www.hallozorg.nl/registeren you can create your personal and cost-free account. HalloZorg is a website that can be accessed via your computer or mobile device. By clicking on 'logging in', you can fill in your email address and a personal password.

Did you forget your password? Please go to www.hallozorg.nl/wachtwoordvergeten and create a new password.



NetworkMAP

Are you able to keep oversight of your social support network? Can you rely on persons within your social network, for example family, friends or home care nurses, for daily care and social support?

NetworkMAP helps you to easily visualize and keep oversight of your social support network members and the type of support you receive.

Figure 8.2. Quick start guide (continued)





Figure 8.3. Format of NetworkMAP - types of social network members

Figure 8.4. Example of a personalized NetworkMAP



Data collection

All patients were followed as individual case trajectories over a five-month period. Data was collected at baseline (T0), 6 weeks into the intervention period (T1) and at the end of the five-month period (T2). At T0, data was collected via observations and interviews. At T1 and T2, data was collected via interviews. Also, during the intervention period (T0 – T2), logdata on the usage of the tool was collected (i.e. each patient verbally consented to collecting the logdata).

Observations

The primary researcher kept track of observational notes that recorded the elderly patients' sense-making and ability to use the tool during the implementation period as well as non-verbal interactions between the researcher and the patients. These observational notes were important in reflection on the implementation process and giving context to the usage of the tool during the researcher's absence (based on the log-data).

Interviews

At T0, the semi-structured interviews focused on the accessibility, relevance and usefulness of the tool. Each patient verbally consented to the interview. A topic list consisted of key questions but during the interview the primary researcher added individual questions relating to specific observations made during the implementation process. Examples of the key questions are: (1) is this intervention of relevance to your situation?, (2) how would you grade the level of difficulty of logging in and engaging with the tool yourself?, (3) what do you think of the design of the tool?, (4) how useful is the information retrieved to making your NetworkMAP?, and (5) who do you believe would benefit most from this intervention?

At six weeks (T1) and five months (T2), patients were briefly interviewed on their usage of the tool via telephone. These interviews focused on retrieving more feedback on the design, accessibility and usefulness of the tool. At T1 and T2, the patients who were still participating were also asked whether they had made changes to their NetworkMAP, by adding or deleting members and moving the network members based on the subjective importance. These changes were discussed with the participants. The answers to the interview questions were written down and anonymised afterwards.

Logdata

For each patient, logdata was registered on their login frequency and the changes made to the NetworkMAP (i.e. adding or deleting network members). The log-data provided insight into the actual usage of the tool over the five-month intervention period. The logdata was saved in a password secured Excel file which only one IT staff member of HalloZorg and the primary researcher had access to.

Data analysis

Data analysis focused on analysing the implementation process as well as the accessibility, relevance and usability of the tool. Based on the observational notes and the logdata, the researchers discussed the type of network members and support of the participating elderly at T0. During these discussions, the researchers categorised the different social networks into different types (i.e. diverse networks, family or friends centred, family or friends contact, isolated or professional contact only).

Interview transcripts were categorized based on the interview questions, to gain better understanding of the accessibility, relevance and usability of the tool. At T0, the anonymised transcripts were discussed with the IT department of HalloZorg, to decide whether the design of the tool needed to be adapted. Also, the interview transcripts at T0 were compared with the answers given in the follow-up interviews (T1 and T2), to gain a better understanding of the factors that influenced the implementation and intervention process. The interview transcripts were frequently discussed in the research team, also taking into consideration the primary researcher's reflection on the implementation process.

RESULTS

Participant characteristics

Participant characteristics of the seventeen elderly participants their mapped their social network at T0 are shown in table 8.1. Ten participants were male and seven patients were female. The higher number of male participants is inconsistent with the Dutch elderly population, of which most are female (Statistics Netherlands (CBS), 2020). The average age of the participants was 71 years. Most participants were widow/widower and lived alone. The marital status of the participants is fairly consisted with the Dutch elderly population, as statistics show that Dutch elderly are most often either married or widow/widower (Statistics Netherlands (CBS), 2020). The living status of the participants, especially the participants between the age of 60 to 80 years, is fairly inconsistent with the Dutch elderly population, as statistics show that elderly in that particular age group most often live with their partner (Statistics Netherlands (CBS), 2020). Participants rated their skill level with the use of technological devices such as laptops, smartphones and tablets. On a scale of 1 to 4 (1 'not skilled', 2 'a little bit skilled', 3 'quite skilled', 4 'very skilled'), the average skill level was 2.

Social network types

Based on their NetworkMAP, four social network types were found. Figure 8.5 illustrates the stories of participants for each network team (based on the observational notes). For eleven participants their social network can be described as a family centric network with frequent contact and support from their social network. These participants described that

Participant	Age	Gender	Highest educational status	Marital status	Living status	Chronic conditions	Self-rated skill level using technological device (e.g. laptop) (1-4)
1	81	Male	Less than high school	Widower	With children	Diabetes, heart failure, COPD, arthritis, problems with stability, prostate problems, visual disability	2
2	65	Male	High school/ technical school	Divorced	Alone	Asthma, urine incontinence, rheumatoid arthritis	2
3	65	Male	College and above	Married	With partner	Heart failure, rheumatoid arthritis, epilepsy	3
4	65	Male	College and above	Registered partnership	With partner	Diabetes, heart failure, damage due to a stroke, COPD, arthroses depression, gout	3
5	70	Male	College and above	Registered partnership	With partner	Damage due to a stroke, cancer, COPD, osteoporosis	3
6	71	Female	Less than high school	Widow	Alone	Asthma, urine incontinence, anxiety problems,	1
7	97	Female	High school/ technical school	Widow	Alone	Heart failure, urine incontinence, arthroses, problems with stability, hearing disability	2
8	81	Female	High school/ technical school	Widow	Alone	Heart failure, urine incontinence, arthroses, problems with stability, depression	1
9	67	Female	High school/ technical school	Widow	Alone	Osteoporosis, COPD	2
10	69	Male	High school/ technical school	Married	With partner	Diabetes, heart failure, Asthma, problems with stability, kidney failure	4
11	67	Female	High school/ technical school	Widow	Alone	Diabetes, damage due to a stroke, COPD, urine incontinence, rheumatoid arthritis, osteoporosis, problems with stability, chronic polyneuropathy	3
12	79	Male	College and above	Widower	Alone	Diabetes, damage due to a stroke, rheumatoid arthritis, problems with stability, visual disability	3
13	68	Female	High school/ technical school	Widow	Alone	Diabetes, COPD, urine incontinence, rheumatoid arthritis, osteoporosis, problems with stability, hearing disability	3

Table 8.1. Participant characteristics (n = 17)

14	61	Male	High school/ technical school	Unmarried	Alone	Damage due to a stroke, COPD, osteoporosis	2
15	68	Female	College and above	Married	With partner	Diabetes, hearing disability, visual disability, urine stoma	4
16	65	Male	High school/ technical school	Registered partnership	With partner	Diabetes, heart failure, cancer, problems with stability, prostate problems, hearing disability	3
17	66	Male	High school/ technical school	Married	With partner	Cancer, Asthma, rheumatoid arthritis, visual disability	3

Table 8.1. Participant characteristics (*n* = 17) (continued)

alongside the care they received from professionals (most often the home care nurse and physiotherapist), they received much support from their partner or (grand)children. This mostly considered of everyday support (e.g. grocery shopping) and emotional support (e.g. companionship). All of these participants had one family member in particular of whom they received much support, for example accompanying them to medical appointments. For three participants, their network could also be described as a family centric network but with little contact and support. All of these participants were widow(er). Though these participants had children and grandchildren, they received little to no visits from them. For two participants, their network can be described as a diverse network. These participants mentioned that they received support from their family but were also member of a hobby club or church group for a long period. For one participant, his network can be described as a restricted network. This participant had lived alone and fairly isolated throughout his life. Although the participant group is relatively small (n = 17), we explored to what extent there are relationships between the participants' background characteristics and the network types.

Figure 8.5. Networl	k types and	participant	stories
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Family centric network with frequent contact and support (<i>n</i> = 11)	One participant had a daughter who lived only five minutes away and visited her everyday. During these visits, she would assist her in everyday tasks such as cleaning, grocery shopping and cooking. Her daughter also accompanied her to medical appointments and managed her finances. As they shared a close personal relationship, she felt able to share all her feelings with her daughter.
Family centric network with little contact and support (<i>n</i> = 3)	One patient had three grandchildren and photos of them hang throughout his house. They would phone him once a month, but only visited him at his birthday and during Christmas. He felt they had forgotten about him after his wife passed away four years ago. He was afraid to share his feelings with his (grand)children, as he did not want to bother them with his sorrows.
Diverse network (<i>n</i> = 2)	One participant had been a member of a model train club for ten years. He knew most of the other members for a long period and had befriended them. Recently, his wife was admitted to a nursing home due to her progressed dementia. After 55 years of marriage and living together, he was suddenly alone at home. Attending his weekly club provided him with emotional support and helped him cope with the situation.
Restricted network (<i>n</i> = 1)	One participant had lived alone and isolated throughout his life. After making some bad decisions in his younger years, he went to prison several times. This led to a broken relationship with his family members. The daily visits of the home care nurse were the only time he would have face-to-face contact with another person. His cat played a pivotal role in his life and was his source for emotional support. By cuddling and talking to her, he felt comforted.

Usage of the tool

At T0, fifteen of the seventeen participants found it valuable to visualise their social network, as it provided a clear overview and insight into their sources for support and potential for more support. These participants found the tool relevant for their situation. The relevance was especially with regard to having an overview of the care professionals involved in their care process. Some participants indicated that they had trouble memorizing the names of all professionals involved and the contact information of all the care organisations. They saw potential in the use of NetworkMAP to create a clear and easily accessible oversight. Two participants found the tool not relevant to their situation, as their social network was relatively small and they could oversee their social network themselves. Most participants indicated that the tool is most relevant for elderly with a large and diverse social network. Also, elderly with relatively small memory problems could benefit from the tool as visualisation could help them keep oversight of their network. However, as memory problems would get worse over time elderly would be unable to understand how to use the tool).

Figure 8.6 shows the usage of the tool in the five-month intervention period. Between T0 and T1 (6-week period), the logdata showed that only four participants had used the tool, primarily to add information (i.e. contact details) to their network members. Between T1 and T2 (3.5-month period), one of the participants had made use of the tool. The interviews at T1 and T2 indicated several reasons for the non-usage of NetworkMAP. The primary reason was that the health situation of the participants of the health of their partner had severely deteriorated over time. Because of this, participants had no time or interest in using the tool. Participants also indicated not using the tool as their social network had not changed over time. Because of this, participants saw no added value in the use of the tool.



Figure 8.6. Usage of NetworkMAP in the intervention period

Participants' and researchers' reflection on the implementation process

The interviews with participants and observational notes showed important insights from both the participants' as well as the researchers' perspective into implementing a technological tool with elderly patients with multimorbidity.

Participants' perspective on the implementation process

First, some participants were hesitant to create an online account for an unknown website and tool. Participants first needed fill in their email address to receive a link to create an account and password. Some participants were afraid they would get hacked if they filled in their email address. Participants were warned by friends and family members not to fill in their contact details or read in the newspaper not to trust unfamiliar websites.

Second, creating a personal NetworkMAP involved too many consecutive steps for the participants to understand and memorize. After logging in, participants first saw the home page and had to click on the 'create NetworkMAP' tab. For each new social network member they wanted to add, they had to fill in their name and contact details in a separate pop-up text box, click on 'done' and then drag them to one of the four squares (i.e. type of network member). The participants expressed that they would prefer if they would be sent to the NetworkMAP directly after logging in. Also, they would prefer if they could type the names and contact details of their network members directly in the four squares.

Third, all participants found it beneficial that the implementation process took place at their home and with the use of their personal technological device they were familiar with. By being in their own home, they felt more comfortable to speak openly. By using their own device, most participants were already familiar with the practical usage of a technological device (e.g. starting a new internet page, logging into their mail account).

Fourth, the participants highly appreciated that they received face-to-face and one-on-one guidance through the process of making their NetworkMAP. The primary researcher took the time to sit down with them, guide them through the process and answer questions. Most participants experienced difficulties making an account and logging into NetworkMAP. Especially the participants with a family network mentioned that their (grand)children usually create online accounts to websites for them and arranged that they log in automatically. For many of these participants, it was the first time they needed to create an account themselves and needed to memorize a password. Therefore, they valued that the primary research took the time to assist them.

Fifth, most participants found the quick start guide a helpful reference resource. Participants expressed feeling overloaded by the abundance of information they received during the implementation process. Having all the login steps and elements of the tool on paper as a reference helped them to better understand how to use the tool. Last, the participants found it important the tool was free of charge. Most participants indicated that they would not want to make an online account or use the tool if there were costs involved.

Researchers' perspective on the implementation process

First, face-to-face and one-on-one guidance through the implementation process is essential when implementing a technological tool with elderly participants. This personal contact was also highly valued by the participants, as mentioned above. Though most participants said to be relatively experienced using a technological device and the Internet, their experience was mostly limited to for example social media (e.g. keeping contact with their network through Facebook) or browsing to news websites. Most participants had created shortcuts to these websites and automatic login. As NetworkMAP was an unknown tool for them, they needed much guidance through the process of creating an account and creating their NetworkMAP.

Second, it is important that participants trust the researcher and understand the research aims. Some participants were hesitant to share their story with an unfamiliar person. It is important for researchers to properly introduce themselves and the purpose of their visit.

Third, implementing a technological tool during house visits is time consuming. Some elderly participants need extra guidance in creating an account (e.g. how to start a new web browser page) and repetition of the steps in using the tool. Also, many participants felt happy that somebody visited them and they were able to have a conversation, regardless of the purpose of this visit. This meant that aside from the implementation process, much time was spent on informal chatting. Moreover, for many participants talking about their social network and social support was emotional. For example, participants would reminisce about their deceased spouse or close family members and friends.

Fourth, the presence of an informal caregiver or close family member/friend helped to engage elderly participants more in the intervention process. In five situations, the partner or son/daughter of participant was present during the implementation process and were able to help participants understand the purpose of the tool. They could also assist the participant through the process of creating a NetworkMAP.

Last, elderly participants often need extra stimulation to engage with a technological tool themselves. Some participants felt less certain about their digital skills and tended to let the primary researcher create the NetworkMAP for them instead of doing it themselves. Therefore, some participants needed extra reassurance that they were capable of engaging with the tool.

DISCUSSION

This chapter first aimed to explore the network types of elderly patients with multimorbidity living at home. Second, we aimed to explore the usefulness and acceptance and the implementation process of the web-based social network intervention with elderly patients with multimorbidity named NetworkMAP.

Though we could not longitudinally examine the effectiveness of the intervention, the intervention did provide insight into the different types of networks that elderly patients with multimorbidity have. In line with other research on social networks of elderly patients (Kennedy et al., 2015; Rogers et al., 2016), the results in this chapter show that elderly patients with multimorbidity have different types of social networks in terms of the type of network members and type of support. Most elderly patients much support on a regular basis from close family members, especially their informal caregiver. Moreover, the results indicate that at T0 most participants found it valuable to visualise their social network. Whether a social network is visualised on paper or via a technological tool, visualisation itself helps individuals to have a clear overview of their network members and the type of support they received. It also helps to identify gaps in the support system or possible sources of support that are more uncommon. For example, consisted with other research on support sources (Rogers et al., 2016), the results in this chapter show how pets are considered a valuable source for (emotional) support by some elderly patients.

With regard to the usage and acceptance of the NetworkMAP tool, the results showed that within the five-month intervention process, the usage of the tool was very low to non-usage. This suggests that the tool was not accepted by the elderly patients as part of their daily life. This non-acceptance of the technological tool could be explained by using the technology acceptance model (TAM) as a heuristic framework (Venkatesh & Davis, 1996). This model consists of two primary factors that influence an individual's behaviour: perceived usefulness (i.e. the extent to which an individual believes that a particular technology will improve his/ her (job) performance) and perceived ease of use (i.e. the extent to which an individual believes the technology is free of effort) (Venkatesh & Davis, 1996). The results in this chapter suggest a low degree of perceived usefulness among the elderly participants. The follow-up interviews at T1 and T2 showed that the participants did not see an added value in using the tool, for example because there were no changes in their social network. With regard to the perceived ease of use, the participants' reflection on the implementation process indicated that for some participants using the tool was not free of effort. Some participants had difficulties using a new tool and understanding and memorizing the different steps. This could have affected their non-intention to use the tool and in turn, the non-usage in daily life.

Based on the results in this chapter, different facilitators and barriers can be identified that are important to take into consideration when involving this specific user group in the implementation process and which could affect the acceptance and usage of a tool. These facilitators and barriers can be categorized into to levels: the participant level and the technology level (figure 8.7).



Figure 8.7. Facilitators and potential barriers

When designing an intervention specifically aimed to help elderly patients visualise and understand their social network, it is important that the intervention is customisable and adaptable to accommodate the changing social context of patients (Wherton, Sugarhood, Procter, Hinder, & Greenhalgh, 2015). Moreover, it is important that the implementation process takes place at an elderly patient's home and patients receive face-to-face, personal, guidance through the process. Though it can be time-consuming, personal guidance trough the implementation process and the training in use of a new technological tool is an essential element engaging elderly patients and stimulating the adaption of the intervention. As shown in the systematic review of Mostaghel (2016), one barrier to elderly accepting technology is a lack of training in the usage of a tool. As was shown in the researchers' reflection, some elderly participants needed extra stimulation to use the tool themselves instead of leaving it up to the researcher, as they felt uncertain about their digital skills. Even though all elderly patients had some experience in using a technological device (e.g. laptop), they needed and highly appreciated personal training in using an unfamiliar and new tool. An understandable quick start guide could act as a supporting reference book when patients to use the tool themselves.

In addition, on a network level, the results in this chapter indicate that the presence and support of a family member (e.g. informal caregiver) helps to engage elderly patients more in the implementation process. A systemic review on elderly patients' acceptance of technology shows that the support from family is an important factor for elderly to accept and adopt technology in their daily life (Mostaghel, 2016).

A potential barrier to the elderly patient's willingness to adopt a technological tool could be their privacy and security concerns (Mostaghel, 2016). As became evident in the participants' reflection on the implementation process, some participants were afraid to create an online account that required filling in their email address and name. Therefore, to stimulate elderly patient's engagement in the implementation process, it is preferable that a web-based tool can be used without the need for filling in personal information. Also, it could be beneficial to connect a new tool with an existing tool that elderly patients use more frequently and are more familiar with, for example Facebook or WhatsApp.

Moreover, a patient's (deteriorating) health status (e.g. ability to process, visual disability) is a potential barrier to engaging elderly patients in the implementation process and adopting the intervention in daily life (Mostaghel, 2016). Some elderly patients that participated in this study had a visual disability. The results in this chapter showed that some patients had difficulties understanding and memorizing all the steps in the intervention process. Though the elderly participants thought that NetworkMAP is beneficial for elderly with small memory problems to keep an oversight of their social network support, their deteriorating health status could lead to less ability to use the tool themselves.

CONCLUDING REMARKS

Based on the implementation process evaluation of NetworkMAP, two important concluding remarks on implementing technological tools for elderly patients can be made. First, it is important that the aim of the intervention, the design and (technological) means used (i.e. type of tool) are in balance. NetworkMAP aimed to enable elderly patients to map their social network and gain more insight into the potential support of their social network. Though most participants did see an added value in visualising their network as it gave an overview of the type of support they received, there was little usage of the tool by the participants. This suggests that although the overall aim of the intervention was achieved, the design and the use of a web-based tool were not suitable for the elderly patients and did not fit within their daily life. Co-designing interventions with elderly patients, especially CHAPTER 8

technological interventions, could help in designing interventions that align with patients' skill level and preferences and to gain more insight into the contextual factors that influence their adoption of an intervention.

Second, integrating tools into existing tools that are familiar to elderly patients could enhance the acceptance and usage of the intervention. The process evaluation in this chapter showed that introducing new technological tools to elderly patients is difficult. The elderly participants had problems 'trusting' the tool and had concerns regarding the privacy and security of the tool as it was unfamiliar to them. Therefore, instead of continuously building new IT infrastructures for each new tool, it could be beneficial to explore how tools could be integrated into tools that elderly patients use on a daily basis, for example Facebook.

To conclude, guiding elderly patients through the implementation process is not only beneficial for the patients, but also gives researchers more context of elderly patients' daily lives. The elderly patients that participated in this study opened their homes and hearts and were more than willing to share their story. Engaging with elderly in the implementation process is thus both beneficial for the elderly patients with multimorbidity as for the researchers.

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CHAPTER 9

General discussion

Many elderly face different challenges due to their multiple chronic conditions (multimorbidity), such as an impaired ability to perform daily living activities or keeping track of the many medical appointments. Since the prevalence of multimorbidity is related to the ageing population, more and more people will face similar challenges as they grow older. At the same time, the trends of decentralization of care, ageing in place and stimulating patients to take on more responsibility in organizing for care and support has led to an emphasis on organizing care in communities closer to patient's homes, more patient involvement and self-management (Pavolini & Ranci, 2008; Price, Surr, Gough, & Ashley, 2020; Tonkens, 2011; Verhoeven & Tonkens, 2013; Vos, van Boekel, Janssen, Leenders, & Luijkx, 2020).

Due to their multimorbidity, these elderly living at home rely on the care and support of a multidisciplinary team of different primary care professionals such as a general practitioner, health care nurses and occupational therapists (Bähler, Huber, Brüngger, & Reich, 2015; Ngangue et al., 2020; van Dongen et al., 2016). Also, they are often supported by their informal caregiver (i.e. often next of kin) or a social network of for example friends and neighbours. Therefore, the multidisciplinary team members, the informal caregiver and the elderly patient interact and are dependent on each other's roles. In these interactions, individuals might have different perceptions on who is part of the team, are not always acquainted, roles are often undefined and individuals could have different perspectives on what is best for the patient. This can cause challenges such as poor communication, power imbalance and lack of trust (Bradley, Ashcroft, & Noyce, 2012; Karam, Brault, Van Durme, & Macq, 2018; Reeves et al., 2015; Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017).

The overall aim of this thesis was therefore to gain more insight into the teamwork and interactions between patients, informal caregivers and primary care professionals and the effect of these interactions on patient involvement and self-management. The thesis is built up along three research questions. The first research question concentrates on the conceptualisation of multidisciplinary primary care teams and members' perspectives on the roles in the team: *What is a primary care team and what are the perspectives of team members on their own role and those of others in the team*? The second research question focuses on how the interactions between patients, professionals and informal caregivers influence the patient in daily life: *How do the relationships between elderly patients, informal caregivers and primary care professionals influence patient involvement and self-management in daily life?* The third and last research question concentrates on the future of care for elderly patients, by examining how the social context of an elderly patient in terms of the team of professionals and social network can be strengthened: *How can teamwork in primary care be improved and social network support be stimulated*?

In the following section, we will summarize the main findings by answering the research questions. In the discussion of this thesis, the theory and research methodology are reflected upon. Lastly, recommendations for practice and future research are offered.

MAIN FINDINGS

Research question 1: What is a primary care team and what are the perspectives of team members on their own role and those of others in the team? Chapter three showed that primary care teams are conceptualised by primary care professionals as teams with a fluid nature and multi-layered (i.e. an inner core layer and multiple outer layers). Their perspectives do not align on who is part of the primary care team and who is part of which layer. For example, the GPs do not consider physiotherapists as part of the core layer, while physiotherapists themselves do consider themselves part of the core. The misalignment of perspectives is related to the degree of relational coordination (chapter three). Our research shows three factors that influence professionals' perception of working as a team: (a) knowing the people you work with, (b) exchanging knowledge and (c) sharing a holistic view of caregiving.

Next, the results of our qualitative interviews with professionals, informal caregivers and patients show that they have different perspectives on the roles of patients and informal caregivers in the team (chapter four). Our research shows that some patients want to take on an active role in the team but have to deal with professionals who treat them as passive bystanders in their own care process or informal caregivers who undesirably act as team leader. Because of this, patients feel misunderstood and take less control than preferred. Also, different primary care professionals in the team can have conflicting perspectives on the role patients should fulfil. As a result, the patients need to balance different and conflicting opinions.

Research question 2: How do the relationships between elderly patients, informal caregivers and primary care professionals influence patient involvement and self-management in daily life? To answer research question two we analysed triads of elderly patients, their caregiver and the most involved health care nurse in their care process. Chapter six shows that patient involvement is influenced by the patient's perception on which role is expected from him/her by his/her informal caregiver and home care nurse (i.e. subjective norms) and the latter two perspectives on the patient's role. For example, our research shows that when a patient believes that his/her informal caregiver or nurse expects to leave the decision-making to the care professional, patients more often perceive themselves as having a passive role.

As described in chapter six, our research showed that (mis)alignments exist regarding the type of behaviour the patient thinks their informal caregiver or nurse expects from them versus how informal caregivers and nurses think the patient should act. Our research shows three underlying factors in the relationships within the triads that are related to this misalignment. These factors are: (a) how well the informal caregiver and nurse know the patient's preferences, (b) the extent to which the patient values a care professional's opinion and (c)

the severity of the patient's medical history. Also, chapter six shows that patient involvement is influenced by the patient's level of perceived social support. Patients who perceive to have little support more often consider having a passive role, while patients who perceive to have much social support more often perceive to share the decision-making with their informal caregiver and/or a care professional such as a GP.

As described in chapter five, our research shows that self-management is influenced by the levels of mutual trust in the triads. Like subjective norms, the level of mutual trust and expectations is shown to both align and misalign in these triads. For example, our research shows misalignments in which the informal caregiver and nurse have little trust in the patient, whereas the patients regards his/her behaviour towards them positively. Patients who have a positive perspective on their behaviour towards their informal caregiver and the nurse are also more confident in their self-management skills. Informal caregivers and nurses who trust the patient also believe more in the patient's self-management ability.

Research question 3: How can teamwork in primary care be improved and social network support be stimulated? The systematic review in chapter seven shows an exponential increase in studies on team interventions in different health care settings which can be categorized into three types of interventions: (1) training (i.e. training based on predefined principles like crew resource management (CRM), simulation or general team training), (2) tools (e.g. checklists and rounds) and (3) organizational (re)design. Most interventions concentrate on improving non-technical skills such as communication, leadership and situational awareness. CRM and TeamSTEPPS show the most potential to improve teamwork in health care. The systematic review shows very little available evidence on team interventions in the primary care setting. A majority of the included studies was conducted in the acute hospital setting; very little in the primary care setting. Studies performed on team interventions in the primary care setting mostly focused on tools and programmes that combine elements of training and tools such as medical team training.

Chapter eight describes the implementation process and lessons learned from the implementation of a digital intervention named NetworkMAP (Network – Mobilizing Active Partnership). The design of this intervention was based on the results of chapter six and seven. Chapter six highlights the importance of social network support in a patient's daily life. In this mixed-methods study, the qualitative research shows that social network size and support resources vary and that social networks consist of multiple support layers. The systematic review in chapter seven shows that most team intervention studies provide little information of the context of intervention as well as the implementation process. NetworkMAP was designed to gain an overview and more understanding of the social support context of elderly patients. The intervention was based on the hypothesis that by visualising an elderly patient's network, they gain more insight into the support of their network and be able to identify possible gaps in their support network. By having this insight, patients would be more able to self-direct social support and self-manage their health by investing in current relationships with network members and developing new relationships when needed. Due to the difficulty of involving elderly patients with multimorbidity in an intervention study with a digital tool, we could not longitudinally examine the effect of the intervention on the patient's self-management ability. Nevertheless, chapter eight shows the diversity of patients' social networks as well as a process evaluation and lessons learned from both the patients' and the researchers' perspectives.

THEORETICAL CONSIDERATIONS

Theme 1: Teams versus networks

The term 'team' is a popular term to examine or address collaborations between professionals. At the beginning of our research project, we followed this trend by adopting the term 'primary care team' to address the collaboration between primary care professionals from different disciplinary backgrounds. However, both in research and practice, what a team is, who its members are and what team goals are is often left open (Allen & Hecht, 2004). A lack of clear conceptualisation affects the generalizability and comparability of research results by comparing apples and oranges and creates difficulties in understanding the relationship between team structure and team performance. Maybe even more important, it can create expectations towards the general lay population on what the team is and what its tasks are that cannot be lived up to.

In this thesis, our conceptualisation of primary care teams is based on the perspectives of primary care professionals themselves. They view primary care teams as fluid entities with a core and outer layers. Their perspectives fit with the stream of literature on team conceptualisation in recent years that questions the boundedness of team, takes on a dynamic perspective of teams and conceptualises teams as fluid entities (Mortensen, 2014; Tannenbaum, Mathieu, Salas, & Cohen, 2012; Wageman, Gardner, & Mortensen, 2012). Following this line of reasoning, it could be argued that from a professional's perspective, primary care teams are correctly labelled as teams based on their fluid team structure.

However, being named a team and acting as a team are different matters. There are multiple assumptions on team processes that underly the fluid character. First, being a multilayered fluid team implies that primary care professionals know each other personally and want to work with professionals from other disciplinary backgrounds, in order to decide jointly which disciplines play an essential role in the caregiving process and form the core layer. Second, it implies that the core members are familiar with each other's knowledge and competence level to coordinate their roles and tasks and are able to identify when and which specific skills of other professionals outside the core are needed. Third, it implies a degree of communication and task coordination between the core members, but also with professionals in the outer layers. The results in our thesis suggest that these implications do not apply to how primary care professionals conceptualise primary care teams, thus we should question whether primary care teams are 'fluid teams'. The primary professionals had different perspectives on who is part of the core layer. Also, they did not always acknowledge the importance of working with other disciplines, were rarely acquainted with each other and scarcely communicated or coordinated tasks. Thus, for primary care teams to act as teams and not only exist in name, it is important to focus on improving team familiarity and team processes.

From a patient's perspective, the term 'primary care team' is too narrow to take all care and support resources of patients into account. The term 'primary care team' in research and practice is often associated with collaboration between care professionals, pre-dominantly by placing the role of the GP central in the team. Especially for elderly patients with multimorbidity, a holistic, person-centred approach that also includes care professionals from psychological and social domains is important (Kodner & Spreeuwenberg, 2002). This goes beyond recognizing the roles of professionals such as psychiatrists, home care nurses and welfare workers, but also acknowledging the essential roles of non-professionals. These include not just the patient and informal caregiver, but the broader social context. In making their personalized social network, the elderly patients in the intervention study highlighted the importance of (emotional) support by among others friends and family, neighbours, volunteers, church communities and even pets (Kennedy, Vassilev, James, & Rogers, 2015; Rogers, Vassilev, Brooks, Kennedy, & Blickem, 2016). Given the policy trends of organizing care and support more at the community level, the roles of these non-professionals will become even more vital in the future. For elderly patients, knowing that you can talk to someone, feeling supported and being able to rely on someone when needed is maybe even more important than complying with medical treatment. This importance and need for social support became even more evident during the recent Covid-19 pandemic. As elderly patients with multimorbidity are considered to be frail, the regulations regarding quarantine and social distancing meant they had little to none face-to-face social contact with others and lived fairly isolated at home. For example, elderly people received no visits from family and friends and were not able to go outside for grocery shopping or visit community centres. This isolation period led to major consequences for the psychological wellbeing of elderly, as elderly felt more lonely and were at greater risk of anxiety or depression (Radwan, Radwan, & Radwan, 2020).

Thus, social support plays a pivotal role in a patient's wellbeing and it is therefore important to conceptualise the care and support context from the patient's perspective. The term primary care team therefore does little justice to the vital roles of different non-professionals. Rather, from a patient's perspective, the term 'patient network' is more appropriate in which the network members might not be linked to each other but are all linked to a central person: the patient. CHAPTER 9

Placing the patient central also means placing his/her goals in life central and focussing on what is needed to achieve these goals. For some patients achieving or enhancing selfmanagement is their goal, while other patients want to be more supported by their informal caregiver or others. To achieve these goals, the quality of relationships and interactions between individuals is essential, irrespective of whether entities are labelled as teams, networks or otherwise. In line with Gittell (2001; 2006; 2008; 2002) among others, this thesis supports the notion that the dimensions of the relational coordination theory are important in strengthening relationships among primary care professionals, but also in triads of professionals, patients and informal caregivers. Dimensions such as frequent communication, shared knowledge and values and mutual respect are essential in high quality relationships. This is supported by our systematic review in this thesis, showing that most team interventions focus on improving non-technical skills. Hence, regardless of the terminology, be it teams or patient networks, the main focal point of attention should be strengthening and enhancing the quality of mutual relationships among professionals and between professionals, patients and informal caregivers.

Theme 2: Tensions in the relationships regarding trust and power

Trust is an essential element for the quality of the relationships in the triads. Throughout this thesis, trust plays an essential role within the different relationships: (a) between patients and primary care professionals, (b) between patients and their informal caregiver and between informal caregivers and primary care professionals and (c) between primary care professionals, specifically between the general practitioner and other professionals.

The relationship between patients and primary care professionals

As concepts such as self-management, patient involvement and shared decision-making are more emphasised, the professional's trust in a patient deserves attention and thus was an important element of this thesis. Self-management refers to how patients cope with the impact of their conditions on a daily life, for example their dietary plan (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Professionals have more control and power over the medical domain (e.g. the right treatment plan) but have to trust the patient's self-management skills. Also, stimulating patient involvement and shared decision-making means investing in a form of partnership between a professional and a patient, in which professionals are willing to share their power and responsibility over the decision-making process. In this partnership, professionals have to trust the patient, for example in providing the correct information and answering questions honestly (Moskowitz et al., 2011; Thom et al., 2011).

Trust between patients and professionals should therefore be seen as a dynamic concept in which trust is bi-directional and exists in different gradations. A patient's trust in a professional is shaped by their, changing, asymmetrical power relationship. In a more traditional perspective, trust in the patient – professional relationship could be seen as "blind faith"

(Brennan et al., 2013). Patients were considered to be in a vulnerable position due to their medical condition and the asymmetrical knowledge of the medical domain. Because of this, they often had to blindly trust the professional's knowledge and competence level. This asymmetrical perceived power relationship is still often evident in the relationship between an elderly patient and the GP. To illustrate, some of the interviewed elderly patients in this thesis referred to the GP as "the doctor in the white coat" who knows what is best for them and who they blindly trust. It is notable that this high level of interpersonal trust of elderly in the GP is also shaped by their high level of trust in health care institutions such as a GP's office or hospitals as places, which is influenced by the media and the general population's confidence in such institutions (Pearson & Raeke, 2000). Contrariwise, a patient's trust in the professional can also be "conditional" (Brennan et al., 2013; Skirbekk, Middelthon, Hjortdahl, & Finset, 2011). Medical knowledge is more and more available and spread through mass media, reducing the information gap between patients and professionals. Not just the younger generation, but also the elderly population, as was evident in this thesis, becomes more critical and vocal. Many patients still trust that professionals have their best interests at heart, but are critical of professionals' advice and do not want to comply without checking other sources (e.g. the internet or asking family for advice) (Skirbekk et al., 2011). Nevertheless, wanting to be critical and actually being critical and being vocal are two different steps. Achieving the latter step is not solely in the hands of patients, but requires a different mindset of professionals as well. Perceived power relationships and dominance of professionals could hinder patients who want to be vocal to do so. To illustrate, our thesis showed examples of elderly patients who want to have a say in the decision-making, but do not speak up out of fear for negative reactions. Thus, professionals need to be aware of the fact that patients do not always blindly trust them and should support them in being vocal.

However, Moskowitz (2011) also indicates that professionals' trust is influenced by their prejudices and stereotyping of patient groups, specifically patients from different ethnic groups or socio-economic status. Patients from ethnic minority groups and from low socio-economic status regions were less likely to be trusted. Though this study focused on a completely different study population (i.e. HIV infected patients with high rates of illicit drug use) than in our thesis, given the large multicultural population in the Netherlands and other western European countries, it is important that professionals are aware of the risks of possible stereotyping.

The relationship between patients and informal caregivers

Informal caregivers play an important role in the care process and many elderly patients with multimorbidity are dependent on their care and support. Given that most informal caregivers are close family members (i.e. spouses or children), this trusting and the personal bond creates an implicit power relationship between a patient and their informal caregiver. Speaking up to an informal caregiver is difficult as this not only affects the patient – caregiver

relationship, but more importantly the relationship between two family members (Bredewold, Verplanke, Kampen, Tonkens, & Duyvendak, 2020). As was shown in this thesis, this could lead to informal caregivers taking on a central role that is not desired by a patient.

The more prominent role of informal caregivers also influences the informal caregiver – professional relationship. Informal caregivers often assist elderly patients to medical appointments and have a degree of control over the decision-making process. Also, the power relationship between an informal caregiver and a professional is shifting, as there is less asymmetry in knowledge and competences. Informal caregivers, especially those who have been involved for numerous years, could and are more able to perform specific care-related tasks (Bonsang, 2009; Weinberg, Lusenhop, Gittell, & Kautz, 2007). Support and training by care professionals is essential for these tasks. However, this prominent role of informal caregivers requires a shift in the professional's perspective: Are professionals able to consider informal caregivers as partners in care and willing to substitute part of their expertise?

The relationship between the GP and other primary care professionals

In the relationships between primary care professionals, power is related to autonomy. Professionals may use their power to protect their autonomy and limit their dependency on other professionals to maintain their power. This could mean that professionals consciously work solo or find allies of other professionals of whom they are sure will not threaten their autonomy (McDonald, Jayasuriya, & Harris, 2012).

Especially in the relationship between the GP and other professionals power plays an important role (Chew-Graham, Slade, Montana, Stewart, & Gask, 2007; Kirby et al., 2008). Chapter one of this thesis showed how some GPs themselves but also other professionals placed the GP in the core layer of this team. GPs coordinate the medical domain and are often gatekeeper to further care (Grol et al., 2018). From a holistic, person-centred, perspective to care from elderly patients with multimorbidity, the psychological and social domains are also essential to the well-being of these patients. This was emphasised in chapter eight of this thesis. The patients who visualised their social network expressed that they were rarely in contact with their GP, as the chronic nature of their condition did not require them to gain frequent medical advice. These patients were more in contact with other primary professionals such as home care nurses, physiotherapists, occupational therapists and welfare workers.

Though GPs play an important in the care for elderly patients with multimorbidity, we should not presume that GPs themselves always want to be a central person in the care process or are not willing to share power. Research on the GPs perspectives on their role in the care for elderly with chronic conditions showed that many GPs acknowledge the importance of teamwork and sharing responsibilities and power with other professionals (Grol et al., 2018; Herzog, Gaertner, Scheidt-Nave, & Holzhausen, 2015). Herzog and colleagues (2015) showed that many GPs do consider themselves to be medical experts, but understand that they are only one important actor in the care for elderly patients with multimorbidity.

Teamwork with other professionals is considered to be important and these GPs trust other professionals' knowledge and expertise. This not only includes practice nurses who work within the GPs office (Schers, Koopmans, & Rikkert, 2009), but also professionals in other domains. Moreover, Wind (2015), who is a GP herself, discusses that the future GP should not solely be a medical professional but also a coach of a multidisciplinary teams. In this latter role, the GP is a team member and responsible for managing the team, delegating tasks and keeping oversight. Each team member has its own responsibilities and tasks and respects each other's boundaries. In this vision, professionals who act as a team can achieve more than working as individuals and power is divided equally. This is optimal for elderly patients with multimorbidity, who need to receive holistic care.

Building trusting relationships

In every type of relationship, building trust and maintaining a trusting relationship evolves over time and can only be shaped under certain conditions. Throughout this thesis, the importance of familiarity, getting to know each other and mutual roles and expectations, is highlighted as an essential element of every relationship.

Between patients and primary care professionals, trust building is associated with the level of longevity and continuity of care and the extent to which positive interactions occur over time (Kramer & Cook, 2004). In other words, trust can only be shaped when the same professional is involved in the care process over a longer period of time and patients and professionals see each other on a regular basis. This implies that primary care teams are fairly stable in terms of the same professionals from different disciplinary backgrounds involved over time. This stability is present for the patient – GP relationship, as many elderly patients are connected to the same GP for a long period of time. Because of this, mutual trust can be built over time. On the one hand, patients will trust their GP when they get more acquainted with their competence and knowledge level. On the other hand, GPs can for example better assess a patient's situation or health literacy and to what extent they can trust a patient's self-management skills.

However, building trust is difficult with regard to the patient's relationship with other primary care professionals. Home care nurses, but also other disciplines such as physiotherapist, work in, large, monodisciplinary teams. Home care organizations more and more try to limit the size of home care teams, but many elderly patients still see different home care nurses throughout the week. This especially accounts for elderly patients who receive care from larger home care organisations. However, for the elderly in the Netherlands, this might change in 2021 due to new agreements in the home care sector. In the 'Leidraad herkenbare en aanspreekbare wijkverpleging', home care organisations, health insurances, municipalities, patient organisations, professional associations and the Ministry of Health, Welfare and Sport have agreed to more intense collaborations between home care organisations active in the same community (ActiZ, Patiëntenfederatie Nederland, V&VN, VNG, VWS, ZN en Zorgthuisnl, 2020). This should lead to limiting the home care personnel shortages and waiting lists. More importantly, the agreement focuses on ensuring that patients receive care from a small and stable team of nurses and have one contact person who oversees their situation.

Trust building is a pivotal aspect in the patient – home care nurse relationship for multiple reasons. Home care nurses are involved in the care process for a longer period of time and are one of the few disciplines that visits a patient at his/her home. Chapter 8 of this thesis showed that for many elderly patients, the house visits of home care nurses are one of the few, if not only, times per day that they can talk to somebody face-to-face. In other words, nurses play a key role in a patient's social wellbeing and can contribute to limiting loneliness. Unfortunately, house visits are often restricted in time to only providing the required care, leaving little room for social talk with patients. In addition, the intimate nature of some the home care nurse's tasks (e.g. assisting in bathing), requires that patients have a long-term trusting relationship with the nurse. Losing your independency and needing assistance in such daily tasks can be difficult to handle for patients, especially those patients who have been fairly independent throughout their life. This dependency will only be harder to deal with without a trusting relationship with the nurses who assists you. In sum, we should not forget how important home care nurses are in a patient's life and thus how essential a trusting relationship between a patient and a nurse is. Therefore, nurses should be facilitated in every way possible, for example by being assigned to specific patients, to build a trusting relationship.

Between patients and informal caregivers, two types of relationships exist. First, since most informal caregivers are next of kin, a *personal* relationship is present in which trust is embedded. Second, giving the role of the informal caregiver in the caregiving process and his/her tasks, the relationship between a patient and informal caregiver can be seen as a patient – *professional* relationship in which trust needs to be build. Especially in situations in which informal caregivers substitute some professionals' tasks (i.e. nursing tasks), informal caregivers' trust in their own knowledge and competences but also the patient's trust in the informal caregivers' skill set grows over time. The more frequent informal caregivers perform certain tasks, the more they will get experienced and trust their own skill level, but also be trusted by patients. This experience can only be achieved when informal caregivers feel supported by professionals (e.g. guidance in performing tasks) and professionals are willing to substitute tasks. This means that primary care professionals need to trust informal caregivers to be able to perform certain care tasks. Therefore, trust in the patient – informal caregiver relationship can only be built when the underlying condition of trust in the informal caregiver giver – professional relationship is met.

In multidisciplinary primary care teams, the role of the GP develops over time as team members get more familiar and trust is built. Grol and colleagues (2018) show that in teams of members who have little shared working experience, GPs tend to take on a more dominant role in the team. As indicated in this thesis, in teams of multidisciplinary professionals who have worked more together over time, team members become more familiar with mutual competences and knowledge level. Because of this, professionals are more likely to accept each other's role, acknowledge the added value of another team member and trust that another professional will act in a certain manner. In these more experienced teams, Grol and colleagues (2018) show that GPs tend to more often share tasks and responsibility with other team members than in teams with little shared working experience, resulting in more equivalence in a primary care team. In sum, it is important that primary care professionals get to know each other and build mutual trust.

Theme 3: Patient involvement

Patient involvement in the decision-making process refers to the role that patients *prefer* and are *able* to take on in the decision-making process regarding their health situation. This thesis emphasises how patient involvement is not an isolated concept, but shaped in the relationships and interactions between patients, informal caregivers and patients.

Thompson's taxonomy of preferred patient involvement shows different levels in involvement, related to the degree of patient power and autonomy (Thompson, 2007). First, in the lowest degree of patient power, patients are not involved, which could be because patients themselves do not want to be involved (e.g. due to the severity of their illness) or because they are, deliberately, excluded by professionals. In this thesis, some patients did not prefer to be involved due to their high level of trust in the professional, primarily the GP, to know what is best for them. Some GPs also did not find it necessary to involve an elderly patient in the decision-making process, as most of the decisions require medical knowledge. Second, patients want to receive information and professionals provide this, but patient power is still limited as professionals take decisions and patients solely consent. Third, in shared decisionmaking patients and often informal caregivers are involved, but it still may be that patients prefer the professional to take the final decision based on their expertise and knowledge. In this thesis, many elderly patients preferred discussing their options with professionals and their informal caregivers, but still highly trusted the professionals and valued their opinion. Fourth, in the highest degree of patient power, patients autonomously make the final decisions, often based on the information they retrieve from professionals (Thompson, 2007). In this thesis, some of the elderly patients expressed a desire to make autonomous decisions.

Preferred patient involvement and subsequently evolving to actual patient involvement is not solely based on either the patient's behaviour or the stimulation of involvement by informal caregivers and professionals at a specific point in time. Based on results in this thesis we could say that there are different phases through which actual patient involvement is shaped. This process is not static, rather it is dynamic and may change over time and depends on the severity of a patient's condition. Especially in cases where patients want a degree of power and involvement, the phases are combined with different challenges. First, CHAPTER 9

patients need to be aware of the level of involvement they prefer and be able to discuss their preferences with their informal caregiver and the involved professionals. This not only means that patients need to speak up, but also that informal caregivers and professionals facilitate this conversation. However, this conversation is often more an exception rather than the rule, as the interviews in this thesis indicate that many informal caregivers and professionals do not ask the patient for his/her preferences and act on what they themselves believe is best. Also, it is questionable whether patients freely express their own preferences as this thesis shows that patients are influenced by what type of behaviour is expected from them. Second, especially with shared decision-making and autonomous decision-making, informal caregivers and professionals need to show explicitly that they 'allow' patients to be involved on their preferred level. Involving patients means that professionals need to shift a degree of autonomy over the decision-making process to patients in the form of increased knowledge, control and responsibility. The elderly in the qualitative interviews in this thesis who want to share or make decisions autonomously still perceive to be passive bystanders in their care process. This raises the question whether professionals, and in most cases the GP, are willing to shift a degree of autonomy and trust to the patient to make the right decisions. Third, through the process of allowing patients to be involved, patients themselves need to perceive the acceptance of their preferred level. Fourth, patients need to express their involvement through their actual behaviour towards their informal caregivers and professionals. Our thesis shows that actual patient involvement is challenged by the behaviour of the informal caregiver, in undesirably taking on a leading role or by professionals who still, unintentionally, fall into a repair reflex. In sum, it is important not to consider patient involvement as a static concept that exists or not exists, but to focus on how relationships and interactions shape patient involvement as a dynamic and iterative process.

Theme 4: The future landscape for care of elderly patients with multimorbidity

In the upcoming years, different (societal) developments will change the landscape of longterm care for elderly patients with multimorbidity. The ageing society and increasing life expectancy questions the sustainability and affordability of the current health and social system. In ten years from now, more than two million elderly aged 75 years or older will live in the Netherlands. At the same time, the demographic changes are expected to lead to more staff shortages in care organisations and less informal caregivers and volunteers to rely on to provide care and support. In the Netherlands, the commission 'Toekomst zorg thuiswonende ouderen' was assigned by the Ministry of Health, Welfare and Sport to give advice on how to organize long-term elderly care in the next decade given the demographic changes, technological developments and affordability of the current system (Commissie Toekomst zorg thuiswonende ouderen, 2020). In 2020, their advice was published in a report titled 'Oud en zelfstandig in 2030. Een reisadvies' (Commissie Toekomst zorg thuiswonende ouderen, 2020). Their report contained three main advices. First, investing in appropriate housing to facilitate elderly to live independently at home for as long as possible. Municipalities alongside housing corporations have the responsibility to ensure a sufficient number of future-proof houses for elderly. Second, more use of digital tools for care delivery. According to the commission, the use of digital tools such as videoconferencing should become the new standard for professionals. Also, elderly themselves need to make more use of digital tools to improve their self-management skills and quality of life. Third, primary care organisations and professionals in both care and support should invest more in collaboration for a more efficient use of scarce resources. This entails not only a strong collaboration between GPs and community nurses, but also for example welfare workers, dentists and pharmacists.

Though delivering care more from a distance by using digital tools such as video-calling is essential for the affordability and sustainability of the elderly care system in the future, we should be critical of the impact on elderly patients' daily lives and wellbeing. Video-calling limits the frequency of face-to-face and physical contact during the day. Face-to-face contact is important for the well-being of elderly patients with multimorbidity, as is also evident in this thesis. Because of this limited face-to-face contact, emotional and social loneliness are becoming larger risks for the elderly population. In the present Covid-19 pandemic, the importance of face-to-face contact to limit loneliness among elderly living at home becomes even clearer. The Netherlands Institute for Social Research showed that the number of socially lonely elderly has doubled in 2020 during the Covid-19 pandemic lockdown (The Netherlands Institute for Social Research, 2020b). Elderly patients lived fairly isolated as they could not receive visits from professionals or for example their (grand)children. Many elderly used video-calling or social media to maintain their social network. Though some professionals already used video-calling for medical consultations before the pandemic, the Covid-19 pandemic boosted the use of video-calling in the professional's practice. For professionals, using video-calling is beneficial. They were still able to assess a patient's situation and to continue the care delivery process. However, for patients, video-calling does not diminish their perceived loneliness. Studies on the effect of the Covid-19 pandemic and social distancing on (elderly) patients' wellbeing highlight how patients need face-to-face contact and long for physical contact (Consortium Coronatijden, 2020; The Netherlands Institute for Social Research, 2020b; van Tilburg, Steinmetz, Stolte, van der Roest, & de Vries, 2020).

In light of the trend of more technology, this may not solely entail the interactions between humans, but could also imply the use of human-like robots. For example, in the ACCRA project (Agile Co-Creation of Robots for Ageing), human like robots were developed and placed at elderly peoples' homes. The first results of this study show that elderly who felt lonely were enthusiastic about the robot and started to consider the robot as their buddy over time (Life Sciences and Health 010, 2020). In sum, face-to-face interactions and physical contact are important for elderly living at home to feel connected to others and reduce loneliness (Consortium Coronatijden, 2020; The Netherlands Institute for Social Research, 2020b).

Moreover, given the increasing overburden rates of informal caregivers, it is questionable how much we can and should rely on them to provide care for chronically ill elderly patients in the future. Especially in informal caregiving for chronically ill elderly patients, informal caregivers are at higher risk to become overburdened. Because of their multimorbidity, care for these patients is often intensive and for a long period. Prevo and colleagues (2018) show that the intensity and duration of caregiving are significant factors associated with higher burden. As the intensity of caregiving increases and informal caregivers need to provide care for a large number of hours per week and over multiple years, they more often feel overburdened. Moreover, children of elderly patients who act as informal caregivers often need to combine their caregiving with a family life and need to work until official retirement age. The overburdening of informal caregivers has become even more evident and problematic in the Covid-19 pandemic. Because of the government regulations, care was scaled down and facilities that provided daytime activities for patients were closed. As a result, many chronically ill patients stayed at home during the day, which put more pressure on informal caregivers to provide care and support and increased their risk of becoming (more) overburdened (Consortium Coronatijden, 2020; The Netherlands Institute for Social Research, 2020a). Feeling (over)burdened has a negative effect on the emotional, psychological and physical state of informal caregivers, such as anxiety, depressing and back injuries (The Netherlands Institute for Social Research, 2020a). In the worst case, it could lead to situations in which caregiving becomes too intense, informal caregivers are unable to provide care and possibly become patients themselves. Thus, how much more should we rely on informal caregivers to provide care in the future?

It is also questionable how much we can rely on a patient's social network for support in the future. The shift in the responsibility and provision of (social) care from the state to municipalities and communities, presumes a prominent role of a patient's social network in delivering support. With the closing of nursing homes, a physical place for natural interactions, contact has disappeared. Therefore, volunteer initiatives for elderly (e.g. buddy projects) and activities within community centres are important in stimulating social contact and limiting social isolation, especially for elderly with limited support from family and friends. The Covid-19 pandemic was exemplary for social cohesion in communities and volunteer initiatives. For example, people offered to do grocery shopping or walk the dog for elderly neighbours who could not leave their house. However, as also questioned by Kim Putters (Head of the Netherlands Institute for Social Research, SCP) in a recent Dutch newspaper, we should not presume that this social cohesion will stand after the pandemic (Couzy, 2020). During a crisis such as the Covid-19 pandemic, people may be more aware of their surroundings. Afterwards, people could fall back into old patterns and be occupied with their own daily work and family life.

METHODOLOGICAL CONSIDERATIONS

Several methodological considerations should be taking into account when interpreting the findings in this thesis. First, involving elderly patients with multimorbidity in research was challenging and had its impact on the heterogeneity of the respondents group and the generalizability of our findings. Also, conducting the research was time-consuming as all patient data was collected in face-to-face interviews. To ensure the criteria of living at home and multimorbidity, patients were approached via primary care professionals (for the interviews) and a large home care organization (for the questionnaire). We were dependent on a patient's consent for sharing their contact details with the research team. Logically, the primary care professionals approached those patients of whom they thought were able, based on the severity of their condition, to understand the purpose of the research and being able to answer interview questions. The elderly patients that consented to sharing their contact details, and ultimately to participate in the research, were mostly patients who were still relatively healthy, active and independent in activities of daily living. Hence, our study population may not fully represent the variety of elderly patients with multimorbidity living at home, especially those patients who are more severely ill and dependent on others for care and support. Though conducting research with elderly patients with multimorbidity is challenging and time-consuming, including this often underrepresented population in research is important and should not be forgotten. As shown throughout this thesis, it not only provides information on their level of health, but also valuable insight into their experiences of ageing with multimorbidity and the possibilities of involvement and self-management.

Second, our specific focus on examining triads (chapters 5 and 6) led to a relatively lower sample size than desirable. Given the challenges of including elderly patients with multi-morbidity in research, the patient response rate was still relatively high (133 patients) and we were able to analyse 39 unique triads of patients, their informal caregiver and the most involved home care nurse. Multilevel analysis is commonly used with nested data such as triads, but due to our small sample size, we were unable to perform such analysis. However, our data on these triads does provide valuable insights into specific relationships and daily interactions within the triads from different perspectives, especially considering the difficulties of including elderly patients with multimorbidity in research. Furthermore, the data on the triads solely focused on the home care nurse as primary care professional. Elderly patients with multimorbidity are often in contact with multiple primary care professionals with different disciplinary backgrounds and their interactions and relationships with patients may differ (as underscored by the findings discussed in chapter 3). Therefore, our findings are not generalizable to triads with primary care professionals other than home care nurses.

Third, we used a mixed-methods design to analyse the interactions and triads instead of social network analysis. Although social network analysis is commonly used to understand the connections and interactions in networks, a mixed methods design was considered as

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the best fit given the research aims. Social network analysis mainly focuses on the structure of a network in terms of the centrality (i.e. distance between individuals) and the density of a network (i.e. the relationship between individuals in terms of the number of connections). This thesis focuses on gaining an understanding of the underlying dimensions of the relationships between patients, informal caregivers and professionals. The use of the mixed methods design was essential to gain a richer understanding of the conceptualisation of primary care teams and patient involvement from multiple perspectives (part A) and the relationships and interactions within the triads (part B). The qualitative findings substantiated or complemented many of the quantitative findings in this thesis. For example, the qualitative interview findings helped to gain a better understanding of primary care professionals' conceptualisation of primary care teams and the underlying factors that influence their perception of working as a team. After consulting a social network analysis expert for advice on the research design, a mixed-methods design was considered most suitable.

Fourth, due to challenges regarding the inclusion of elderly patients with multimorbidity in the intervention study, we were unable to perform a longitudinal intervention study as anticipated at the start of the research project. Elderly patients could only be included when they had access to a personal electronic device such as a laptop or tablet and were sufficiently digitally skilled to fairly independently make their personal social network map. Though a sufficient number of elderly patients who had access to an electronic device consented to participate prior to visiting these patients' homes, at the first visit many elderly decided to drop-out because they did not feel competent enough. Moreover, continuity of participation was limited by the progression of their illness and concerns on excessive intrusiveness in their personal space. Because of these difficulties in the data-collection, we were unable to collect sufficient data for longitudinally analysis of the effect of the intervention on the patient's self-management ability. However, our process evaluation (chapter 8) improves our understanding and provides lessons-learned on conducting intervention studies with elderly patients with multimorbidity. For example, the presence of an informal caregiver in the implementation process helps to engage elderly patients more in the implementation process.

IMPLICATIONS FOR PRACTICE

This thesis reveals several implications for practice. On the individual level (i.e. within the triads), it is important to invest in building relationships in which there is attention to building mutual trust and role expectations are made explicit. Patients, informal caregivers and primary care professionals all have different perceptions on their own role and different expectations on others' roles in the care delivery process. If these perceptions and expectations in the relationships, which in turn could impact the care delivery process. Chapter four of this

thesis shows that elderly patients with multimorbidity could feel uncomfortable addressing their preferred role as they are afraid for negative reactions. Thus, it is important that primary care professionals initiate and facilitate this discussion with their patients and the informal caregiver. As preferences could change over time as a patient's health status deteriorates, this discussion should not only take place at the intake, but should be repeated on a regular basis. For primary care professionals, this means that they should not solely focus on a patient's medical needs, but on a patient's life as a whole. What role do patients see for themselves in the caregiving process? Do they want to be involved in the decision-making process or self-management of their health? What do they expect from their informal caregiver and what does he/she expects from the patient in return? In addition, what do primary care professionals expect from the patient and their informal caregiver?

On an organisational level, it is important that primary care professionals themselves invest in building stronger multidisciplinary teams that not solely exist in name, but also act as one team. Elderly patients with multimorbidity benefit most from a situation in which primary care professionals work together to provide holistic care. At the same time, multidisciplinary teamwork is pivotal for the sustainability and affordability of the future elderly care. Investing in multidisciplinary teamwork is one of the key advices of the commission 'Toekomst zorg thuiswonende ouderen' (Future care for elderly living at home), as mentioned earlier. Based on this thesis, one of the key first steps in building multidisciplinary primary care teams is getting to know each other and discuss mutual roles expectations and competence and knowledge levels. It is important that professionals 'know the face behind the name' and make the effort to familiarize themselves with the other professionals involved in the care process. This could also include informal caregivers or other social network members. As professionals are often under time-pressure, video-calling or meeting each other at a patient's home could help to get to know each other.

On the government level, policy-makers need to be aware of the heterogeneity in elderly patients preferred level of involvement in the decision-making process. In the current health care policy, patient involvement is emphasised as an essential element in all professional-patient relationships. Professionals need to stimulate patients to be more involved in the decision-making process of their care situation. However, in this thesis it is clear that some patients feel most comfortable when the professional or their informal caregiver takes the lead in the decision-making process and prefer a more passive role for themselves. So should primary care professionals stimulate patient involvement and understanding about a patient's preferred role in the triads of patients, their informal caregiver and primary care professionals. Every level of patient involvement on the continuum of non-involvement to autonomous decision-making should be considered as acceptable, as long as patients feel comfortable with their role and informal caregiver and primary care professionals acknowledge and accept this role.

RECOMMENDATIONS FOR FUTURE RESEARCH

This thesis focusses on the conceptualisation of primary care teams and the interactions between patients, their informal caregiver and primary are professionals and the effect of these interactions on patient involvement and self-management. Based on the findings reported in this thesis, several recommendations for future research will be given. First, studies on (conceptualising) primary care teams around elderly patients with multimorbidity should not solely focus on professionals in the medical domain (e.g. GP, home care nurse), but also include professionals from the psychological and social domain (e.g. psychologists, social workers, community coaches). In conceptualising primary care teams (chapter three) and analysing the interactions between patients, their informal caregivers and professionals (chapter four), we solely focused on the perspectives of professionals in the medical domain. However, given that elderly patients with multimorbidity highly value emotional and social support (chapter eight) and the need for a holistic, person-centred approach, professionals from these domains can play an important role in a patient's life. Thus, it is important to gain more understanding of their conceptualisation and perspectives on roles within primary care teams. In addition, the interactions between professionals in the psychological and social domain with patients and their informal caregiver could be further explored.

Second, more research that specifically focuses on triads of patients, their informal caregivers and professionals is needed in order to enrich our understanding of their interactions and the effect on patient involvement and self-management. Analysing triads, as was done in this thesis (chapters five and six), provides valuable insights into relationships and daily interactions from all perspectives. In this thesis, we specifically focussed on the triads between patients, their informal caregiver and home care nurses. As elderly patients with multimorbidity receive care and support from multiple professionals from different disciplinary backgrounds, it is important that future research on triads also includes other professionals than nurses.

Third, research on trust in the patient-professional or patient-informal caregiver relationship should pay specific attention to the trust of professionals and informal caregivers in the patient. Chapter eight specially focuses on their trust in the patient, but research on this topic is still scarce (Wilk & Platt, 2016). Given the emphasis on patient involvement and self-management in health care policy, the competence level of patients and their actions are becoming more important factors in the care delivery process. Professionals need to be able to trust that patients are competent enough and will act in an appropriate manner, for example adhere to treatment plans.

Last, studies on team interventions or co-design interventions with (elderly) patients should not solely report on the effectiveness of an intervention, but also pay specific attention to the context and critically reflect on the implementation process. The systematic review in this thesis (chapter seven) shows that team intervention studies provide little information on the intervention. Chapter eight provides valuable insights into the challenges of implementing an intervention with a hard-to-reach respondent group such as elderly patients with multimorbidity. Insights into the context and implementation process are crucial to understand better what contextual and process factors influence the (non)effectiveness of an intervention and provides lessons-learned for implementing similar interventions in other contexts.

CONCLUSION

This thesis has demonstrated how the mutual relationships and interactions between elderly patients with multimorbidity, their informal caregivers, the involved primary care professionals and the broader social network shape patient involvement and self-management. As became clear in the stories of Mrs. C and Mr. F in the introduction, the context of caregiving and social support for elderly patients with multimorbidity is diverse. This implies that stimulating more patient involvement or self-management does not apply to all elderly patients. It also implies that there is no "one size fits all' approach to strengthening mutual relationships within the triangle of care for these elderly patients. Nevertheless, in every triangle is it important that individuals familiarize themselves with each other, share mutual role expectations and acknowledge the importance of each other's roles for the patient. Achieving alignment between a patient's perception and expectation of their involvement and self-management level and the expectations of their informal caregiver and primary care professionals is challenging. However, alignment is essential for building trusting relationships within each triangle and to provide holistic, patient-centred, care and support for all elderly patients with multimorbidity living at home.

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SUMMARY

In the past decades, the number of elderly patients with multimorbidity (e.g. two or more chronic conditions) has rapidly increased and will increase further in the upcoming years. In many western European countries, health care policy focuses on the trends of decentralisation of care, ageing in place and stimulating patients to take on more responsibility over their health situation. This had led to more emphasis on organizing care closer to a patient's home (i.e. preferably within a patient's social network), more patient involvement and more self-management. Because of their multimorbidity, these elderly patients receive care and support from primary care teams consisting of multiple professionals from different disciplinary backgrounds and organisations and often also an informal caregiver. Many elderly patients with multimorbidity are also supported by individuals in their broader social network, for example friends or neighbours. In this care and support context, elderly patients with multimorbidity, their informal caregiver and the care professionals involved share mutual relationships and are dependent on each other's roles. However, research has shown that in these type of interactions, individuals are not always familiar with each other, have different perceptions on each other's roles and different expectations about what is best for the elderly patient. This can cause challenges such as lack of trust and poor communication, which ultimately affect the caregiving process. This thesis aims to provide more insight into primary care teams and the relationship between elderly patients with multimorbidity, their informal caregiver and primary care professionals and the effect of these interactions on patient involvement and self-management. The thesis consists of three parts in which the concept of primary care teams and the mutual relationships between elderly patients, informal caregivers and care professionals are explored.

Part A of this thesis focuses on the conceptualization of primary care teams and the role of elderly patients with multimorbidity in primary care teams and in the decision-making process regarding their health situation. First, a mixed methods design was used to explore the perception of primary care professionals on the concept of primary care teams. A survey study among 152 primary care professionals from 12 different disciplinary backgrounds and 32 interviews with primary care professionals was conducted. To obtain more understanding of the role of elderly patients regarding patient involvement, 64 interviews with elderly patients, informal caregivers and primary care professionals from different disciplinary backgrounds were conducted. Chapter 3 describes the conceptualization of primary care from the perspective of primary care professionals and the factors that influence their perception of working as a team. The relational coordination theory describes the interrelation between different formal and social processes in interactions (e.g. frequency of communication, shared knowledge, mutual respect and trust) that could influence professionals' perception of who is part of the team. Our results show that primary care professionals conceptualize primary care teams as entities with a fluid nature and consisting of multiple layers (e.g. inner core and multiple outer layers). However, their perceptions of which disciplines are

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part of the team and belong to the inner core of the team misalign. This misalignment can be related to the (low) degree of relational coordination between professionals from different disciplinary backgrounds. The qualitative results show that professionals' perception of working as a team is influenced by three factors. First, it is important that professionals are familiar with each other. Knowing the people creates a level of familiarity and trust that could positively influence communication and coordination. Second, professionals from different disciplinary backgrounds need to feel a necessity for communicating and exchanging knowledge. Third, primary care professionals need to share a holistic view on the caregiving process. Professionals should truly believe in the added value of teamwork and therefore be intrinsically motivated to work as a team.

In chapter 4, we focus in detail on the daily interactions between elderly patients with multimorbidity, informal caregivers and primary care professionals. We explored the perceptions of all three groups on patient involvement in the decision-making process. Our results show that elderly patients, informal caregivers and care professionals all have different perspectives on the extent and level of patient involvement in the decision-making process. Though most professionals found it important to involve patients in the decision-making process, in practice, patients were not always involved. The informal caregiver can be seen as a proxy for the patient and can step in when patients are unwilling or unable to be involved themselves. Moreover, we identified three challenges that could impact patient involvement. First, some patients are unwillingly treated as passive bystanders in the decision-making process in which professionals make decisions for them instead of with them. Patients may want to be active participants but are hesitant to do so because of possible negative reactions. Second, patients have to balance conflicting ideas and opinions of primary care professionals about the desirable level and how to stimulate patient involvement. Third, patients, but also professionals, may have to deal with informal caregivers who attribute a central role to themselves and undesirably act and speak on behalf of the patient.

Part B of this thesis focuses on the interactions within the triads of elderly patients, their informal caregiver and the most involved home care nurse in the caregiving process. We focused on two interaction processes (i.e. mutual trust and subjective norms) in relation to patient involvement and self-management. The results in part B are based on data on 39 unique triads of elderly patients, their informal caregiver and the most involved home care nurse. This data was collected via structured face-to-face interviews with elderly patients with multimorbidity living at home and a questionnaire among their informal caregiver and most involved home care nurse. **Chapter 5** focuses on the level of trust that informal caregivers and home care nurses have in elderly patients, the extent of alignment of mutual trust within the triads and the relationship between trust and self-management. Most studies solely focus on the patient's trust in their care professional and do not take the level of trust of professionals in their patients into consideration. As trust is embedded in the interactions within

the triads, we specifically focused on analysing trust from all perspectives, taking the level of trust of the informal caregiver and nurse in the patient into account. Our results show that within the 39 unique triads, both alignment and misalignment on the level of trust exist. In the majority of the triads there were misalignments. The misalignments especially occur when an informal caregiver or home care nurse has little trust in the patient, but the patient believes he or she acts in a appropriate manner towards both. The results also showed that the level of trust of an informal caregiver or home care nurse was not significantly related to an elderly patient's self-rated self-management ability. This means that when an informal caregiver or nurse have much trust in the elderly patient, the elderly patient him/herself does not automatically believes more in his or self-management ability. However, we did found a positive relationships between the informal caregiver's and nurse's level of trust and their perception of the elderly patient's ability to self-manage their health. This means that when informal caregivers and nurses trust patients, they more often believe that patients are able to self-manage their health.

In chapter 6 we explore how subjective norms within the triads and patients' perceived social support influence the role that patients take on in the decision-making process (i.e. patient involvement). To create a deeper understanding of how subjective norms and social support are shaped within the triads and influence patient involvement, we also conducted 21 interviews with elderly patients, informal caregivers and nurses. Subjective norms are social norms and refer to the type of behaviour we believe is expected from us by others. For example, how elderly patients think their informal caregiver expects them to act in the decision-making process. For the dyads with in the triads (i.e. patient – informal caregiver and patient – nurse), we compared the subjective norms of patients with the perceptions of the informal caregivers and nurses themselves on patient involvement by calculating difference scores. The lower the difference score, the more alignment within a dyad. Our results show that patients and informal caregivers more often than patients and nurses align on the role that patients should have in the decision-making process. Also, when patients perceive to have a shared or passive role in the decision-making process, they more often believe that their informal caregiver or nurse expects them to take on this role. The qualitative interviews indicate three factors related to these alignments. First, familiarity, meaning how well informal caregivers and nurses are informed on a patient's role preferences. Second, the extent to which informal caregivers value a care professional's opinion or try to steer the patient into a different direction. Third, the severity of a patient's medical situation influences patients', informal caregivers' and nurses perceptions on the patient's role in the decision-making process.

With regard to perceived social support, the results show that elderly patients' social networks differ in size, type of network members and frequency of contact and support. Like the primary care team conceptualization in chapter 3, **chapter 6** shows that social networks are seen as having concentric circles of importance. The circle closest to the patient most often consists of an informal caregiver, followed by a circle of (close) friends and family and finally a circle of for example neighbours and social groups. Elderly patients who perceive to have a high level of support from their social network more often believe to have a shared role in the decision-making process.

Part C of this thesis focuses on how teamwork in primary care can be improved and social network support can be stimulated. We conducted a systematic literature review to gain a broad overview of team interventions in all healthcare settings aimed at improving team performance between 2008 and 2018. Also, in the third part of this thesis we evaluate the process of implementing a web-based social network tool for elderly patients with multimorbidity living at home. Chapter 7 describes the outcome of the systematic review. Of the original search of 6025 studies, 297 studies met the inclusion criteria. The team interventions can be categorized into three types of interventions. First, training, which includes training based on the crew resource management principles (CRM), but also simulation or general team training. Second, interventions that revolve around using tools such as (de) briefing checklists and rounds. The category tools was subdivided into tools that structure, facilitate or trigger teamwork in healthcare. Third, the category organisational redesign focuses on interventions with a (re)designing structure to stimulate team processes and functioning. Lastly, a *programme* is a combination of the three previous types. Overall, most intervention studies focused on improving non-technical skills such as decision-making and coping with stress. Also, the systematic review showed that very little intervention studies were performed in the primary care setting; most were performed in the acute hospital setting.

Chapter 8 reflects on the implementation process of a technological social network intervention named NetworkMAP (Network - Mobilizing Active Partnerships). Engaging elderly patients in technological interventions is difficult. Therefore, in chapter 8 we identify lessons-learned (i.e. barriers and facilitators) of implementing a technological intervention for elderly patients. The intervention aimed to enable elderly patients with multimorbidity living at home to visualize their social network and to gain more insight into the gaps and potential for social support in their network. In total, 17 elderly patients created their personalized NetworkMAP on their personal electronic device. Each patient received faceto-face and personal guidance through the implementation process at their homes. The results show that the size and type of social network and received support vary between elderly patients. In most cases, elderly patients had a family centric network (with often an informal caregiver) and frequent contact with their social network members. Though the usage of the tool decreased in the five-month intervention period, the results showed that most elderly patients valued the ability to visualize their social network in order to gain more oversight over their social network support. Based on the participants' and researchers' reflection on the implementation process, we identified multiple facilitators and barriers to implementing technological tools for elderly patients on two levels: the participant level

and the technology level. On the participant level, the facilitators were (a) implementing the technology at a patient's home and on their personal electronic device, (b) face-to-face guidance through the implementation process and (c) the presence of an informal caregiver during the implementation process. The barriers were: (a) patients' low level of trust in their digital skills, (b) a patient's health status and (c) patients' perception of the added value of the technology. On the technology level, the implementation is facilitated when (a) a technological tool is free of charge, (b) has a customisable and adaptable design and (c) is accompanied by an understandable quick start guide as a reference book. The concerns of elderly patients regarding the privacy and security of the tool create a potential barrier.

Finally, in the general discussion in chapter 9 the main findings, theoretical and methodological considerations and implications and recommendations for practice and future research are presented and discussed. With regard to the terminology, whether to speak of teams or network, the appropriate term is dependent on the perspective one takes. From a professional's perspective, the term 'primary care team' fits with the fluid nature of teamwork between professionals from different disciplinary backgrounds. However, a recommendation for practice is that primary care professionals need to invest more in building multidisciplinary primary care teams that not only exist in name, but also act as a team to provide holistic care. From a patient's perspective, the term 'team' is too narrow to take the broad context of care and support resources into account. From this perspective, the term 'patient network' is more suitable, recognizing the essential roles of professionals from the psychological and social domains and non-professionals (i.e. the informal caregiver and social network). Regardless of the terminology, we plea that in order to provide holistic and patient-centred care, the focus should be on strengthening and enhancing the mutual relationships within the triangle of elderly patients, their informal caregiver and care professionals. Building trusting relationships takes time and is challenged by power imbalances and misaligning role expectations. A recommendation for practice is therefore that care professionals initiate and facilitate discussions with their patients and informal caregivers on mutual role expectations and preferences. Also, within these relationships and through daily interactions, actual patient involvement and self-management are shaped. On the government level, the recommendation for practice is therefore that policy-makers need to be conscious that more patient involvement and self-management does not apply to all elderly patients. Rather, every level of patient involvement and self-management on the continuum of non-involvement to autonomous decision-making is appropriate, under the condition that patients are comfortable with their role and this role is accepted by their informal caregiver and the primary care professionals. To conclude, in every triangle it is essential that patients, their informal caregiver and the involved primary care professionals familiarize themselves with each other, discuss mutual role expectations and focus on building trust. Aligning perceptions and expectations is challenging but key to creating a context in which elderly patients with multimorbidity living at home receive the holistic, patient-centred, care and support they need.

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Het aantal ouderen met multimorbiditeit (twee of meer chronische aandoeningen) is in de afgelopen decennia sterk gestegen en zal de komende jaren nog verder stijgen. In het gezondheidszorgbeleid in veel West-Europese landen ligt de focus op de trends van decentralisatie van zorg, zo lang mogelijk thuis blijven wonen en het stimuleren van patiënten tot het nemen van meer verantwoordelijkheid over hun eigen gezondheid. Dit heeft geleid tot een grotere nadruk op het organiseren van zorg dicht bij een oudere patiënt (bij voorkeur in het eigen sociale netwerk), meer betrokkenheid van patiënten in het besluitvormingsproces en meer zelfmanagement. Door hun multimorbiditeit ontvangen deze oudere patiënten zorg en ondersteuning van eerstelijnsteams bestaande uit professionals met verschillende achtergronden en werkzaam in verschillende organisaties. Veel ouderen hebben ook een mantelzorger. Daarnaast worden ouderen met multimorbiditeit vaak ook gesteund door individuen in hun bredere sociale netwerk, zoals hun vrienden of buren. In deze context van zorg en ondersteuning delen ouderen met multimorbiditeit, hun mantelzorger en de betrokken professionals wederzijdse relaties en zijn ze afhankelijk van elkaars rollen. Echter, onderzoek toont aan dat binnen deze interactie individuen elkaar niet altijd kennen, verschillende percepties hebben van elkaars rollen en verschillende verwachtingen over wat het beste voor de patiënt is. Dit kan leiden tot problemen zoals een gebrek aan vertrouwen of slechte communicatie. Deze problemen hebben uiteindelijk invloed op het zorgproces. Dit proefschrift heeft tot doel om meer inzicht te krijgen in eerstelijnsteams en de relaties tussen ouderen met multimorbiditeit, hun mantelzorger en eerstelijnsprofessionals. Hierbij is aandacht voor het effect van deze relaties en de interacties op de betrokkenheid van patiënten in het besluitvormingsproces en zelfmanagement. Het proefschrift bestaat uit drie delen, waarin het concept eerstelijnsteams en de onderlinge relaties tussen oudere patienten, mantelzorgers en eerstelijnsprofessionals nader uitgediept worden.

Deel A richt zich op de conceptualisatie van eerstelijnsteams en de rol van ouderen met multimorbiditeit in eerstelijnsteams en het besluitvormingsproces rondom hun gezondheidssituatie. Allereerst is een combinatie van kwantitatieve en kwalitatieve onderzoeksmethoden toegepast om de perceptie van eerstelijnsprofessionals van het concept eerstelijnsteams te exploreren. Een vragenlijstonderzoek onder 152 eerstelijnsprofessionals met 12 verschillende achtergronden en 32 interviews met eerstelijnsprofessionals zijn uitgevoerd. Om meer begrip te krijgen van de mate van betrokkenheid van oudere patiënten in het besluitvormingsproces zijn 64 interviews met oudere patiënten, mantelzorgers en eerstelijnsprofessionals afgenomen. **Hoofdstuk 3** beschrijft de conceptualisatie van eerstelijnsteams vanuit het perspectief van de eerstelijnsprofessionals en de factoren die invloed hebben op hun perceptie van werken als een team. In de relationele coördinatie theorie wordt de wederzijdse relatie tussen verschillende formele en sociale interactieprocessen beschreven (bijvoorbeeld de frequentie van communicatie, gedeelde kennis, wederzijds respect en vertrouwen) die invloed kan hebben op de perceptie van professionals van wie wel of geen onderdeel van het team is. De resultaten laten eerstelijnsteams zien als fluïde entiteiten die bestaan uit verschillende lagen (een kern en meerdere buitenlagen). Echter, de percepties van de professionals van welke (andere) disciplines deel uitmaken van het team en de kern van het team verschillen. Deze verschillende percepties kunnen gerelateerd zijn aan een lage mate van relationele coördinatie tussen professionals met verschillende disciplinaire achtergronden. De kwalitatieve resultaten laten drie factoren zien die invloed hebben op de perceptie van de professionals over het werken als een team. Allereerst is het belangrijk dat professionals elkaar leren kennen. Door elkaar te kennen wordt een context van vertrouwen in elkaar gecreëerd die een positieve invloed kan hebben op de communicatie en coördinatie van taken. Daarnaast moeten professionals met verschillende achtergronden de noodzaak inzien van communicatie en kennisuitwisseling. Tot slot helpt het als eerstelijnsprofessionals een holistische benadering van het zorgproces delen. Professionals die geloven in de toegevoegde waarde van het werken als een team, zijn meer intrinsiek gemotiveerd om ook als een team te werken.

In hoofdstuk 4 ligt de focus op de dagelijkse interacties tussen oudere patiënten met multimorbiditeit, mantelzorgers en eerstelijnsprofessionals. We exploreerden de percepties van alle drie de groepen van de betrokkenheid van patiënten in het besluitvormingsproces rondom hun gezondheidssituatie. De resultaten laten zien dat oudere patiënten, mantelzorgers en eerstelijnsprofessionals verschillende perspectieven hebben op de mate van betrokkenheid van patiënten in het besluitvormingsproces. Hoewel de meeste professionals aangaven het belangrijk te vinden om patiënten te betrekken werden patiënten in de praktijk niet altijd betrokken. Mantelzorgers werden gezien als vertegenwoordigers van patiënten die niet zelf willen of niet zelf betrokken kunnen worden. Daarnaast laten de resultaten drie uitdagingen zien die invloed hebben op de mate van patiënt betrokkenheid. Ten eerste, sommige patiënten worden als passieve toeschouwers in het besluitvormingsproces behandeld waarbij professionals besluiten voor hen nemen in plaats van samen met hen. Sommige patiënten willen actief participeren in het besluitvormingsproces maar durven uit angst voor mogelijke negatieve reacties dit niet kenbaar te maken. Ten tweede, professionals kunnen conflicterende ideeën en meningen hebben over de gewenste mate van betrokkenheid en hoe betrokkenheid van patiënten het beste gestimuleerd kan worden. Patiënten moeten in deze verschillende ideeën en meningen een balans vinden. Ten derde, patiënten, maar ook professionals, kunnen te maken hebben met mantelzorgers die een centrale rol in het besluitvormingsproces opeisen en ongevraagd namens de patiënt spreken.

Deel B van dit proefschrift richt zich op de interacties in de triades van oudere patiënten, hun mantelzorger en de thuiszorgverpleegkundige die het meest betrokken is in hun zorgproces. Hierbij ligt de focus op twee interactieprocessen (wederzijds vertrouwen en subjectieve normen) in relatie tot de betrokkenheid van patiënten in besluitvorming en zelfmanagement. De resultaten in deel B zijn gebaseerd op data over 39 unieke triades van oudere patiënten, hun mantelzorger en de meest betrokken thuiszorgverpleegkundige. Voor deze dataset zijn

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interviews met ouderen afgenomen en is een vragenlijst onder hun mantelzorger en de thuiszorgverpleegkundige uitgezet. Hoofstuk 5 richt zich op de mate van vertrouwen die mantelzorgers en thuiszorgverpleegkundigen in de patiënt hebben, in hoeverre de ervaren mate van wederzijds vertrouwen van elk individu in de triades met elkaar overeenkomt en de relatie tussen vertrouwen en zelfmanagement. De meeste studies onderzoeken met name het vertrouwen dat patiënten in professionals hebben. Er is nog weinig aandacht voor de mate van vertrouwen van professionals in hun patiënten. Doordat vertrouwen een integraal onderdeel van de interacties in de triades is, analyseerden wij vertrouwen vanuit alle perspectieven. Hierbij was specifieke aandacht voor de mate van vertrouwen van mantelzorgers en thuiszorgverpleegkundigen in de patiënt. De resultaten laten zien dat de mate van ervaren vertrouwen in de triades zowel kan overeenkomen als verschillen. In de meeste triades hadden de individuen een verschillende ervaring. Deze verschillende ervaringen komen met name voor wanneer een mantelzorger of thuiszorgverpleegkundige weinig vertrouwen in de patiënt heeft, maar de patiënt zelf denkt dat hij of zij op een correcte wijze richting beide handelt. Daarnaast laten de resultaten geen relatie zien tussen de mate van vertrouwen van de mantelzorger en thuiszorgverpleegkundige en de ervaren mate van zelfmanagement van de patiënt. Dit betekent dat wanneer een mantelzorger of thuiszorgverpleegkundige veel vertrouwen in de patiënt heeft, de patiënt niet automatisch meer gelooft in zijn eigen zelfmanagement competenties. Desalniettemin was er een positieve relatie tussen de ervaren mate van vertrouwen in de patiënt van zowel de mantelzorger als de thuiszorgverpleegkundige en hun perceptie van de zelfmanagement competenties van de patiënt. Dit betekent dat als mantelzorgers of thuiszorgverpleegkundigen de patiënt vertrouwen, zij vaker ook geloven dat een patiënt de juiste zelfmanagement competenties heeft.

In hoofdstuk 6 wordt geëxploreerd hoe subjectieve normen en ervaren sociale steun invloed hebben op de rol van patiënten in het besluitvormingsproces. Om meer begrip te krijgen van hoe subjectieve normen en sociale steun gevormd worden hebben we ook 21 interviews met oudere patiënten, mantelzorgers en thuiszorgverpleegkundigen afgenomen. Subjectieve normen zijn sociale normen en doelen aangaande wat men denkt dat anderen qua gedrag van hen verwacht. Een voorbeeld is de rol in het besluitvormingsproces die volgens patiënten door hun mantelzorger van hen verwacht wordt. In elke dyade in de geanalyseerde triades (patiënt - mantelzorger dyade en patiënt - thuiszorgverpleegkundige dyade) zijn de subjectieve normen van patiënten vergeleken met de daadwerkelijke verwachtingen van hun mantelzorger en de thuiszorgverpleegkundige door verschilscores te berekenen. Hoe lager de verschilscore, hoe meer de subjectieve norm van de patiënt en de daadwerkelijke verwachting van de mantelzorger of thuiszorgverpleegkundige met elkaar overeenkomen. De resultaten laten zien dat in de dyade van patiënt en mantelzorger de subjectieve norm van de patiënt vaker overeenkomt met de daadwerkelijke verwachting van de mantelzorger dan tussen patiënten en thuiszorgverpleegkundigen. Daarnaast laten de resultaten zien dat patiënten die een gedeelde of passieve rol in het besluitvormingsproces ervaren ook vaker denken dat deze rol door hun mantelzorger of de thuiszorgverpleegkundige van hen verwacht wordt. De interviewresultaten laten drie factoren zien die invloed hebben op de mate van verschil in percepties. Ten eerste, de mate van vertrouwdheid in een triade, doelend op hoe goed een mantelzorger en thuiszorgverpleegkundige op de hoogte zijn van de voorkeuren van een patiënt. Ten tweede, de mate waarin mantelzorgers waarde hechten aan de mening van een professional of de patiënt in een andere richting proberen te duwen. Tot slot heeft de ernst van de medische situatie van de patiënt invloed op de daadwerkelijke verwachting van mantelzorgers en thuiszorgverpleegkundigen over de rol die patiënten in het besluitvormingsproces zouden moeten aannemen.

Met betrekking tot de ervaren sociale steun laten de resultaten zien dat de sociale netwerken van oudere patiënten verschillen in grootte, type personen in het netwerk en de frequentie van contact en steun. Net als in de conceptualisatie van eerstelijnsteams in hoofdstuk 3 laat **hoofdstuk 6** zien dat sociale netwerken worden gezien als bestaande uit meerdere concentrische cirkels waarbij de patiënt centraal staat. In de cirkel direct om de patiënt heen zit vaak een mantelzorger. In de tweede cirkel zitten (naaste) vrienden en familie en in de laatste cirkel zitten bijvoorbeeld buren of buurtverenigingen. Oudere patiënten die veel sociale steun ervaren hebben vaker het gevoel dat zij een gedeelde rol in het besluitvormingsproces rondom hun gezondheidssituatie hebben.

Deel C van dit proefschrift richt zich op de vragen hoe teamwerk in de eerstelijnszorg verbeterd kan worden en hoe sociale steun in sociale netwerken gestimuleerd kan worden. Een systematische literatuur review is uitgevoerd om overzicht te krijgen van team interventies in alle gezondheidszorgcontexten tussen 2008 en 2018 die gericht zijn op het verbeteren van teamprestaties. Daarnaast wordt in deel C van dit proefschrift het implementatieproces van een online sociaal netwerk hulpmiddel voor oudere patiënten met multimorbiditeit geëvalueerd. Hoofdstuk 7 beschrijft de resultaten van de systematische literatuur review. Van de oorspronkelijke zoekopdracht van 6026 studies voldeden 297 studies aan alle inclusiecriteria. De team interventies kunnen in drie categorieën verdeeld worden. Allereerst de categorie training. Deze categorie omvat training interventies die gebaseerd zijn op de principes van crew resource management (CRM) maar bijvoorbeeld ook simulatietraining of generieke team training. Ten tweede zijn er interventies rondom tools zoals instructies en checklijsten. Deze categorie kan verder onderverdeeld worden in tools die teamwerk in de gezondheidszorg structureren, faciliteren of stimuleren. De derde categorie, organisational redesign focust op interventies met een herstructurerend element en die zich richten op het stimuleren van team functioneren en team processen. Tot slot, een programme team interventie is een combinatie van de drie categorieën. De meeste interventies zijn gefocust op het verbeteren van niet-technische competenties zoals besluitvorming en omgaan met stress. Daarnaast laat de systematische literatuur review zien dat de meeste interventies in een

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ziekenhuissetting zijn uitgevoerd, terwijl maar weinig interventies in de eerstelijnszorgsetting zijn uitgevoerd.

Hoofdstuk 8 reflecteert op het implementatieproces van een technologische sociale netwerk interventie genaamd NetworkMAP (Network - Mobilizing Active Partnerships). Het betrekken van oudere patiënten bij technologische interventies is lastig. In **hoofdstuk 8** zijn daarom de leerervaringen (belemmerende en faciliterende activiteiten) van de implementatie van een technologische interventie voor oudere patiënten gepresenteerd. Deze interventie had als doel om thuiswonende oudere patiënten met multimorbiditeit in staat te stellen hun sociale netwerk te visualiseren om zo meer inzicht te krijgen in de mate van en type steun die ze momenteel ontvangen en de potentie voor meer of andere steun. In totaal hebben 17 oudere patiënten hun persoonlijke NetworkMAP op hun eigen laptop gecreëerd. Elke patiënt is thuis bezocht en individueel begeleid bij het implementatieproces. De resultaten laten zien dat de sociale netwerken en het type steun dat patiënten ontvangen verschillen. De meeste patiënten hadden een netwerk dat voornamelijk bestaat uit familieleden (onder andere een mantelzorger) met wie zij frequent contact hebben. Hoewel het gebruik van het hulpmiddel in de interventie periode (5 maanden) afnam, waardeerden de meeste oudere patiënten de mogelijkheid tot het visualiseren van hun sociale netwerk. Dit gaf hun de mogelijkheid om meer inzicht te hebben in de mate van en type steun die zij ontvingen. Op basis van reflectie van de oudere participanten en het onderzoeksteam zijn meerdere belemmerde en faciliterende activiteiten in het implementatieproces met ouderen geïdentificeerd. Deze activiteiten kunnen onderverdeeld worden naar activiteiten op het participant niveau en het technologie niveau. Op het participant niveau zijn de faciliterende activiteiten: (a) het implementeren van de technologie bij een patiënt thuis, gebruikmakend van hun eigen computer, (b) persoonlijke en individuele begeleiding bij het implementatieproces en (c) de aanwezigheid van een mantelzorger tijdens het implementatieproces. De belemmerende activiteiten zijn: (a) een lage mate van vertrouwen in hun eigen digitale competenties, (b) de gezondheidssituatie van de patiënt en (c) de perceptie van de patiënt van de toegevoegde waarde van de technologie. Op het technologieniveau wordt implementatie gefaciliteerd wanneer (a) het technologische hulpmiddel gratis is, (b) het ontwerp individueel aanpasbaar is en (c) het begeleid wordt door een snelstartgids als naslagwerk voor patiënten. De bezorgdheid van patiënten over de privacy en veiligheid van het hulpmiddel is een potentiële belemmering in het implementatieproces.

Tot slot worden in **hoofdstuk 9** de belangrijkste bevindingen, theoretische en methodologische reflecties en aanbevelingen voor de praktijk en verder onderzoek gepresenteerd. Met betrekking tot de terminologie, teams of netwerken, is de geschikte term afhankelijk van vanuit welk perspectief je kijkt. Vanuit het perspectief van de professionals van hun samenwerking met andere professionals sluit de term 'eerstelijnsteams' aan bij hun conceptualisatie van teams als fluïde entiteiten met meerdere lagen. Een aanbeveling voor de SAMENVATTING

praktijk is dat eerstelijnsprofessionals investeren in hun relatie met professionals met een andere disciplinaire achtergrond, zodat teams niet alleen in naam bestaan maar ook handelen als één team dat gezamenlijk holistische zorg levert. De term 'eerstelijnsteam' wordt vaak geassocieerd met een samenwerking tussen professionals uit het medische domein. De resultaten in dit proefschrift laten zien dat vanuit het perspectief van de patiënt professionals uit het psychologische en sociale domein, maar ook niet-professionals (de mantelzorgers en het bredere sociale netwerk) een essentiële rol spelen in hun dagelijkse zorg en ondersteuning. Daarom is vanuit het perspectief van de patiënt de term 'patiënt netwerk' meer geschikt om recht te doen aan hun brede context van zorg en ondersteuning. Ongeacht de gebruikte terminologie is het voor holistische en patiëntgerichte zorg belangrijk om te focussen op het versterken en verbeteren van de wederzijdse relaties in de driehoek van oudere patiënten, mantelzorgers en de betrokken eerstelijnsprofessionals. Het bouwen van een vertrouwensband kost tijd en wordt beïnvloed door machtsverschillen en verschillende verwachtingen over rollen. Een aanbeveling voor de praktijk is daarom dat professionals een gesprek met patiënten en hun mantelzorger hebben waarin wederzijdse verwachtingen over een ieders rol en voorkeuren besproken kunnen worden. In de wederzijdse relaties en in de dagelijkse interacties in de driehoek worden ook de betrokkenheid van patiënten in het besluitvormingsproces en zelfmanagement gevormd. Een aanbeveling voor de praktijk op het beleidsniveau is dat beleidsmedewerkers bewust worden dat meer betrokkenheid of zelfmanagement niet voor alle oudere patiënten geldt. Iedere mate van betrokkenheid en zelfmanagement op het continuüm van geen betrokkenheid tot autonoom beslissen is goed, zolang patiënten zichzelf comfortabel in hun rol voelen en deze rol door hun mantelzorger en de betrokken professionals geaccepteerd wordt. Concluderend, het is in iedere driehoek belangrijk dat oudere patiënten, hun mantelzorger en de betrokken professionals vertrouwd raken met elkaar, wederzijdse rol verwachtingen bespreken en bouwen aan een vertrouwensband. Percepties en verwachtingen afstemmen en op één lijn krijgen is een uitdaging, maar essentieel voor het creëren van een context waarin thuiswonende oudere patiënten met multimorbiditeit de holistische en patiëntgerichte zorg en ondersteuning ontvangen die zij nodig hebben.

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Een zeer grote dank naar al mijn lieve oud-collega's van HSMO, mijn academisch team zonder wiens steun en gezelligheid mijn vier jaar op de universiteit een stuk saaier waren geweest. Bedankt voor de vele gezellige lunches, waardevolle gesprekken en jullie feedback tijdens de science meetings. Mijn surprise baby shower zal ik nooit vergeten! Zonder iemand tekort te doen wil ik graag een paar mensen in het bijzonder bedanken. Anne Marie, zonder jouw email met de vraag "is deze vacature niet iets voor jou?" was ik wellicht nooit gaan promoveren bij ESHPM. Sinds onze samenwerking in het QUASER project hebben wij een band opgebouwd die voor mij nog steeds van grote waarde is. Ondanks dat we elkaar soms weinig tegenkwamen, stond je voor mij klaar op de momenten dat ik je nodig had en pushte je mij om het beste uit mezelf te halen. Isabelle, onze persoonlijke gesprekken waarin ik openlijk mijn onzekerheden kon delen heb ik zo ontzettend nodig gehad en zal ik nooit vergeten. Bedankt dat je deur altijd open stond voor mij en je lieve spontane e-mailtjes om mij er even aan te herinneren dat ik het kon. Mathilde, al snel groeiden we van collega's naar kamergenoten en matties (en ben ik je mattie blijven noemen!). Onze dagelijkse gesprekken over de meest uiteenlopende zaken (vooral gerelateerd aan eten) en flauwe grappen maakten iedere werkdag een stukje leuker. Jouw drive om je proefschrift eigen te maken en je eigen weg te volgen heb ik altijd bewonderd en als voorbeeld gezien voor mijn eigen werk. Bedankt dat je er altijd voor mij was en mij pushte om door te zetten. Lieke, sinds jouw begintijd als onderzoeksassistent tot mijn vertrek zijn wij vrijwel altijd kamergenoten geweest. Bedankt voor het vele lachen en de gesprekken over onze toekomstdromen. Nathalie, bedankt voor alle gezelligheid op de kamer en onze waardevolle sparringsessies. Aline, wat was het altijd gezellig om met jou op een kamer te zitten. We hebben samen wat afgelachen, vaak onder het genot van een tosti! Het was ontzettend fijn om samen van gedachten te wisselen, inclusief zwangerschap en baby-gerelateerde adviezen. Sandra, dank voor alle gezelligheid, met name tijdens de lunches. Het vele schakelen tussen Duits, Nederlands en Engels zorgde vaak voor

de nodige hilariteit aan de lunchtafel. Carien, jij had altijd de unieke kracht om mijn soms chaotische gedachten te ordenen en de rust te bewaren. Hiermee hielp je mij altijd weer een stap verder. Bedankt voor je luisterend oor en voor alle hulp.

Daarnaast is er een aantal ESHPM-collega's die ik zeker niet wil overslaan. Marcello, op een verder lege 6^{de} verdieping was jij de eerste die mij op mijn eerste werkdag aansprak. Al snel hadden we een klik en groeide onze band uit tot een vriendschap met vrijwel dagelijks gesprekken over van alles en nog wat (om maar een paar te noemen: parfum, culturele verschillen, beroemde schrijvers en je ervaringen van wonen en parkeren in Amsterdam), maar er was ook altijd ruimte om mijn twijfels met je te bespreken. Na het spotten van jouw one-of-a kind Mini Cooper in de parkeergarage deed ik vrijwel een dagelijks bezoekje naar HCG om even bij te praten. Ik hoop dat we ooit weer samen een dansje kunnen doen op Bollywood muziek zoals op mijn bruiloft. John, niet alleen voor de studenten maar ook voor mij was je steun van grote waarde. In onze gedeelde liefde voor lekker eten (of kan ik beter zeggen: snacks?) vonden wij elkaar. Bedankt voor alle gezellige lunches, van Maria's Cantina tot Indonesisch buffet en take-out pizza. Ik hoop dat je altijd de waardering krijgt die je verdient.

Mijn medebestuurders van (toen nog) jBMG, wat was het fijn om samen met jullie over het PhD-beleid te sparren! Samen hebben we een mooie basis gelegd waar toekomstige PhD-studenten hopelijk veel profijt van zullen hebben. Dara, dank voor alle gezelligheid, met name samen de mysteries van Monument Valley (prinses Ida!) oplossen in de kleine kamertjes van HCG. Daniëlle, ons heerlijk etentje bij jou thuis zal ik niet snel vergeten. Hopelijk kan ik in de toekomst nog een keer van jouw kookkunsten genieten.

Medebestuurders van de activiteitencommissie: samen activiteiten organiseren was iedere keer weer een feestje! Timo, Martijn en Wouter, wat hebben we toch samen een mooi lustrumfeest neergezet! De aanloop naar het feest toe was eigenlijk al een mini-feestje op zich waarin onze creativiteit geen grenzen had (welke thema's zijn niet de revue gepasseerd?!). Timo, door de jaren heen hebben wij een mooie vriendschap opgebouwd waarin geen onderwerp te gek was om niet te bespreken. Dat er geen dag voorbij ging zonder even bij elkaars kamer binnen te lopen of een kop koffie te drinken waren waardevolle afleidingen die ik zo nodig had.

Ook wil ik graag mijn lieve collega's van ZorgImpuls bedanken! Ik ben blij dat ik onderdeel mag uitmaken van een geweldig team van mensen dat er samen naar streeft om het leven van mensen en de zorg te verbeteren. Ik ben trots op alle successen die wij samen hebben behaald, maar vooral dat we ondanks alle drukte altijd oog voor elkaar hebben en tijd vrijmaken voor een persoonlijk gesprek. Ik hoop dat we dit snel weer face-to-face kunnen voortzetten. Lieve Mo, wat is de omslag van mijn proefschrift mooi geworden! Ik vond het ontzettend leuk om dit geheime mini-project samen met jou te doen, waarbij ik de luxe kreeg om uit meerdere prachtige schilderijen te kiezen. Jouw enthousiasme en creatieve instelling hebben wat mij betreft een waar meesterwerk opgeleverd, waar een beetje van ons beiden inzit. Robert, ik heb al vaker tegen je gezegd dat ik jouw oog voor mij als persoon en steun zeker niet als vanzelfsprekend beschouw en daarom extra waardeer. Bedankt voor jouw vertrouwen om mij als informatiemanager aan te nemen, zeker gezien ik na twee maanden al met zwangerschapsverlof ging. Maar vooral bedankt voor de ruimte die je gaf om mijn proefschrift af te maken. Ik kijk uit naar een mooie toekomst bij ZorgImpuls.

Lieve Willemijn, van collega's bij HSMO naar collega's bij ZorgImpuls! Jij was één van de eerste personen die ik tegenkwam bij HSMO en dat zorgde voor een warm welkom. Gekscherend riep ik weleens dat jouw welkom voelde als 'onder moeders vleugels', maar eigenlijk zit er wel een kern van waarheid in. Je hebt een natuurlijke vibe en het talent om mensen op hun gemak te stellen, wat niet alleen van waarde voor mij was maar ook voor vele anderen. Wat was ik dan ook blij toen ik hoorde dat je bij ZorgImpuls bleef! Onze flauwe humor (die soms net op het randje was en alleen wij begrepen), vele gesprekken over lekker eten (satéeeh!!) en verre reizen maakten van elke dag een feestje. En dat je van iedere dag een feestje moet maken door de kleine successen te vieren heb ik van jou geleerd. Ik ben ontzettend blij dat ik nog steeds nauw met jou kan samenwerken en dat we als zelfbenoemde datanerds onze liefde voor data kunnen delen (team Wiki! Of gaan we toch maar voor Kiwi?). Maar ik ben vooral trots dat jij als paranimf aan mijn zijde staat.

Door het schrijven van mijn proefschrift besef ik nog meer dat een netwerk van mensen zoals ik dat in mijn leven heb geen vanzelfsprekendheid is. Hierdoor is de liefde en steun die ik van mijn vrienden en familie mag ontvangen van grote waarde. Phoewa, dankjewel dat mij altijd hebt gepusht om het beste uit mijzelf te halen. Je bent mijn bonusmoeder. Joey, Rodney, Sabine en Isabelle, jullie zijn de beste broers en zussen die ik wensen kan. Op naar meer chillings waar ik niet op tijd weg hoef om de volgende dag vroeg op te staan om aan mijn proefschrift te werken. De 'vriendengroep', in het bijzonder Kishan en Armand, bedankt dat jullie mij hebben geïntroduceerd in de wereld van Risk. De vele potjes die we speelden in het weekend zorgde voor de nodige afleiding. Ik hoop snel weer van jullie te winnen.

Lieve Denise, lief vriendinnetje, zoals jij bent, zijn er maar weinig op deze wereld. In onze dertien jaar vriendschap (jeetje wat worden we oud!) hebben wij samen veel meegemaakt. Niet alleen op de mooie momenten - met als hoogtepunt onze reis naar Thailand - maar ook op de verdrietige momenten - zoals het verlies van onze naasten - staan we altijd naast elkaar. Ook al kunnen we elkaar niet meer zo vaak zien als vroeger, we weten dat het altijd goed zit. Dankjewel voor al je bemoedigende woorden, lieve kaartjes, spontane cadeautjes en heerlijke etentjes samen. Op naar nog vele mooie jaren als vriendinnen. En we gaan onze belofte om weer samen een mooie reis te maken als we oud zijn zeker waarmaken!

Ma en Aarti, ik prijs mijzelf gelukkig dat ik jullie schoondochter en schoonzus mag zijn. Bedankt voor alle gezelligheid, het lekkere eten, het vele lachen (vooral doordat we altijd hetzelfde op dezelfde toon zeggen, toch Aarti!?), maar vooral jullie liefde. Jullie liefde was een goede afleiding voor de stress en hielp mij er altijd weer bovenop als ik er doorheen zat. Aarti, nu heb ik tijd zat om ons in te schrijven voor tv-spelletjes! Lingo eerst toch?

Lieve Vandana (Died), voor mij ben je niet alleen de beste zus, maar vooral mijn kracht- en inspiratiebron. Al op jonge leeftijd heb jij de wereld laten zien wat doorzettingsvermogen inhoudt. De periode waarin jij ernstig ziek was heeft ertoe geleid dat ik besefte dat er in de (Nederlandse) gezondheidszorg nog veel te verbeteren valt en daarom besloot ik Gezondheidswetenschappen te gaan studeren. Ik heb de grootste bewondering en respect voor hoe je in het leven staat en wat je hebt bereikt. Samen met jou genieten van een sterrendiner of de wereld verkennen is het leukste wat er is. Hopelijk kunnen wij mijn promotie snel vieren met lekker eten (Fred?), of misschien een trip naar Singapore? Het is moeilijk in woorden uit te drukken hoeveel jij voor mij betekent. Ik ben ontzettend trots en dankbaar dat jij aan mijn zijde staat als paranimf, of zoals je zelf zegt, als mijn engel.

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You can kiss your family and friends goodbye and put miles between you But at the same time you carry them with you In your heart, your mind, your stomach Because you do not live in a world But a world lives in you

Frederick Buechner

CURRICULUM VITAE

PhD Portfolio List of publications About the author

PHD PORTFOLIO

Name: Kirti Devika Doekhie

Department: Erasmus School of Health Policy and Management

PhD period: 2014 – 2020

Promotor: Prof. Dr. Jaap Paauwe

Copromotors: Dr. Martina Buljac-Samardžić & Dr. Mathilde Strating

Courses	Year
Tutor skills for Problem-Based Education (PGO)	2014
Mentoring	2014
Supervising small groups	2014
Qualitative interviewing	2014
Course basis didactics	2014
Project Management for PhD students	2015
Presenting and networking	2015
Academic Writing in English for PhD students	2015
Thesis supervision	2016
Speak up my dear	2018
LinkedIn	2018

Presentations	Year
Oral presentation <i>'Primary care professionals' perspective on working as a team</i> '. European Forum for Primary Care (Amsterdam, the Netherlands)	2016
Oral presentation ' <i>Are you part of the team? The role of elderly patients with multimorbidity in primary care teams.</i> ' European Health Management Association (EHMA), (Porto, Portugal)	2016
PhD project presentation at the Center for Excellence in Primary Care, (San Francisco, USA)	2016
Poster presentation 'My Care Map.' Global Forum for Integrated Care (Singapore)	2018

Attended seminars and conferences	Year
Conference ZonMW 'Kennis in de Buurt' (Nieuwegein, The Netherlands)	2014
Workshop Dr. Sanna Laulainen 'critical management and unconventional research methods (Rotterdam, The Netherlands)	2015
Dutch HRM Conference (Utrecht, the Netherlands)	2015
Nictiz MeetUP E-Health (Rijswijk, The Netherlands)	2015
Seminar In voor Zorg 'De wijkverpleegkundige en het sociale wijkteam' (Utrecht, The Netherlands)	2015
Presentation David Coghlan 'action research'	2017

Teaching activities	Year
Mentoring 1 st year Bachelor students	2014 - 2015
Tutor workgroups Introduction to healthcare	2014 - 2015
Grading assignments Bachelor internship 'Blik op zorg'	2014 - 2015
Tutor workgroups Organization Science (Bachelor)	2014 - 2018
Supervising Bachelor theses	2016 - 2018

Research collaborations	Year
Visiting scholar at the Center for Excellence in Primary Care, University of California (San	2016
Francisco, USA)	

Additional activities	Year
Board Member of PhD Council ESHPM	2015 - 2017
Board member of activity committee ESHPM	2015 - 2017

LIST OF PUBLICATIONS

International publications

Doekhie K.D., Buljac-Samardzic M., Strating M.M.H., Paauwe, J. (2017). Who is on the primary care team? Professionals' perceptions of the conceptualization of teams and the underlying factors: a mixed-methods study. *BMC Family Practice*, *18*(111), 1-14.

Doekhie K.D., Strating M.M.H., Buljac-Samardzic M, van de Bovenkamp H.M, Paauwe J. (2018). The different perspectives of patients, informal caregivers and professionals on patient involvement in primary care teams. A qualitative study. *Health Expectations, 21*(6), 1171-1182.

Doekhie K.D., Strating M.M.H., Buljac-Samardzic M., Paauwe, J.. (2019). Trust in older persons: A quantitative analysis of alignment in triads of older persons, informal carers and home care nurses. *Health & Social Care in the Community*, *27*, 1490-1506.

De Marchis E.H., Doekhie K., Willard-Grace R., Olayiwola J.N. (2019). The Impact of the Patient-Centered Medical Home on Health Care Disparities: Exploring Stakeholder Perspectives on Current Standards and Future Directions. *Population Health Management*, 22(2):99-107.

Doekhie, KD., Buljac-Samardzic, M., Strating, M.M.H. Paauwe, J. (2020). Elderly patients' decision-making embedded in the social context. A mixed-method analysis of subjective norms and social support. *BMC Geriatrics*, 20(53), 1-15.

Buljac-Samardzic, M., Doekhie K.D & van Wijngaarden, J.D.H. (2020). Interventions to improve team effectiveness within health care: a systematic review of the past decade. *Human Resources for Health*, *18*(2), 1-42.

Dutch reports

Kirti. D. Doekhie, Anke J.E. de Veer, Jany D.J.M. Rademakers, François G. Schellevis, Anneke L. Francke. (2014). NIVEL Overzichtstudies: Ouderen van de toekomst. Verschillen in de wensen en mogelijkheden voor wonen, welzijn en zorg. Utrecht: Netherlands institute for health services research (NIVEL).

ABOUT THE AUTHOR

ABOUT THE AUTHOR

Kirti Doekhie was born in Nieuwegein on November 6th 1989. She studied Health Care Policy and Management at the Erasmus University Rotterdam. She obtained her Master's degree in Health Care Management in 2012. Thereafter, she continued to study a premaster in Law and obtained a Master's degree in Health Law in 2014. During this master, she worked as a junior researcher at the Netherlands institute for health services research (NIVEL). After graduating, Kirti started working as a PhD candidate at the Erasmus School of Health Policy and Management (ESHPM). Her PhD project focused on the relationships between elderly patients with multimorbidity and their care professional and support network. In 2016, she worked as a visiting scholar at the Center for Excellence in Primary Care of the University of California in San Francisco (USA) during a period of two months. The results of her PhD project were published in international peer reviewed journals and presented at national and international conferences. Kirti was involved in different courses in the Bachelor programme of ESHPM. She currently works as an information manager and an advisor at the Regionale Ondersteuningsstructuur (ROS) ZorgImpuls.

Kirti Doekhie: kdoekhie1@gmail.com

APPENDIX

Questionnaire teamwork in primary care

Ba	ckground characteristics
1.	Date of birth (dd/mm/jjjj):////
2.	Gender
	□ Male
	□ Female
	□ Other, namely
3.	What is your highest completed eduation level?
	□ Secondary school
	□ Secondary vocational
	□ Bachelor degree
	Master degree
	□ Other, namely
4.	What is your disciplinary background?
	General practitioner
	General practitioners assistant
	Physiotherapist
	Remedial therapist
	Occupational therapist
	\square Speech therapist
	Primary care psychologist
	□ Primary care dermatologist
	□ (District) nurse
	Helping assistant
	Geriatric specialized practice nurse
	□ Other namely
	,,,

5. How many years have you been active as a professional in your field of expertise?

......Years

Primary care team

The next set of questions focus on your teamwork with professionals from other disciplinary backgrounds and the relationship and communication with these professionals.

6. How many team members does your team consist of? If there is a large variation, please give an average:

..... members

7. Which of the following primary care disciplines do you consider part of your team? You may select multiple options.

- □ General practitioner
- □ General practitioners assistant
- □ Physiotherapist
- □ Remedial therapist
- □ Occupational therapist
- □ Speech therapist
- □ Primary care psychologist
- □ Primary care dermatologist
- Dietician
- □ (District) nurse
- □ Helping assistant
- □ Geriatric specialized practice nurse
- □ Other, namely.....

	A. How frequently do you communicate with each of this disciplines about a patient?		B. Do these disciplines communicate timely with you?		C. Do these disciplines communicate accurate with you?		D. In case of problems regarding the care for a patient, do these professionals work together with you to fix these problems?	
	Never	←→Always	Never	→Always	Never←→Always		Never←→Always	
General practitioner	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
General practitioner assistant	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Physiotherapist	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Remedial therapist	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Occupational therapist	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Speech therapist	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Primary care psychologist	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Primary care dermatologist	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Dietician	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
(District) nurse	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Helping assistant	NA	12345	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Geriatric specialized practice nurse	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	12345
Other, namely	NA	1 2 3 4 5	N.v.t.	12345	N.v.t.	12345	N.v.t.	1 2 3 4 5

8.	Please fill in all the quest	ions for all disciplines	that you have selec	ted at question 7.

	E. To what degree do these disciplines understand your role in the team?		F. To what degree do these disciplines respect you?		G. To what degree do these disciplines share your goals for the care of your patients?	
	Neve	Never←→Always		Never←→Always		r←→Always
General practitioner	NA	12345	NA	1 2 3 4 5	NA	12345
General practitioner assistant	NA	1 2 3 4 5	NA	1 2 3 4 5	NA	12345
Physiotherapist	NA	12345	NA	1 2 3 4 5	NA	12345
Remedial therapist	NA	12345	NA	1 2 3 4 5	NA	12345
Occupational therapist	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
Speech therapist	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
Primary care psychologist	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
Primary care dermatologist	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
Dietician	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
(District) nurse	NA	12345	NA	1 2 3 4 5	NA	1 2 3 4 5
Helping assistant	NA	12345	NA	12345	NA	1 2 3 4 5
Geriatric specialized practice nurse	NA	12345	NA	12345	NA	12345
Other namely	NA	12345	NA	12345	NA	12345

9. If you have any additional remarks or feedback regarding the questionnaire, please feel free to write these down below in the text box.

You have reached the end of this questionnaire. We kindly ask you to check whether you have filled in all the questions. Thank you so much for your time and effort.